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UNDERSTANDING THE RELATIONSHIPS BETWEEN SURVIVORSHIP CARE PLANS AND SURVIVOR LEVEL OUTCOMES AMONG BREAST AND COLORECTAL CANCER SURVIVORS

JESSICA DANIELLE AUSTIN

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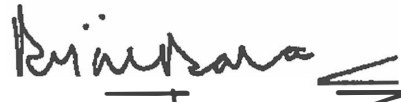
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2019

DEDICATION

To James and Tisa Austin

I dedicate this work to my parents for their unyielding love, encouragement, and support.

“You have brains in your head. You have feet in your shoes. You can steer yourself ANY direction you choose” – Dr. Seuss

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by

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PREFACE

The basis for this dissertation research stems from my academic, professional, and personal experiences. The provision of cancer care is complex resulting in incomplete or inconsistent implementation of interventions, policies, and guidelines into real-world settings, thereby, reducing effectiveness. Over the years I have developed a desire to put the patient in the center of cancer care and to think beyond the clinical encounter. In my experience with cancer care, I recognize that patients are encountering the healthcare system at a vulnerable time. Therefore, it is important to understand the viewpoint of the patient while balancing the complexities of the system. However, the patient is often overlooked when delivering patient-centered care.

My long-term goal is to become an independent researcher applying implementation science principles to cancer prevention and control interventions, policies, and guidelines in real-world clinical and community settings. As I continue to build a program of research, I strive to become a leader in developing pragmatic, efficient, and effective cancer prevention and control programs that real-world clinical and community settings can leverage to improve cancer outcomes. Ultimately, I do not want to lose sight of the purpose of what I want to do, which is to help and serve others.

ACKNOWLEDGEMENTS

I would like to express my deep and sincere gratitude to my dissertation committee for giving me the opportunity to conduct research and providing invaluable guidance throughout this endeavor. It has been a great honor and privilege to work and study under their guidance. I want to personally thank my chair, Dr. Marlyn Allicock, and my supervisor Dr. Bijal Balasubramanian for their empathy, friendship, and mentorship. I owe much of my growth as an individual researcher to them and my predoctoral fellowship committee. I also want to extend my heartfelt thanks to Rikki Ward and Patricia Chen for their integral roles in coordinating this research and assisting with the analysis.

I am extremely grateful to my family and friends for their love, prayers, and sacrifices. A special thanks to Garrett Stinchcomb for his understanding, sacrifices, and unwavering support. He played an integral role in helping me see this challenge through to the end. Finally, I would like to acknowledge the research support provided by the UTHealth School of Public Health Cancer Education and Career Development Program and the support provided by NCI R01CA203856l Project CONNECT.

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PURPOSE: Cancer survivors have complex journeys following the completion of active treatment. The Institute of Medicine and other high-profile organizations have recommended and mandated the use of a survivorship care plan (SCP) despite mixed evidence supporting the impact of SCPs on key survivor-level outcomes. The purpose of this dissertation was to understand the complex relationship linking the delivery of SCPs and to relevant survivor-level outcomes.

STUDY GROUP: This dissertation focuses on breast and colorectal cancer survivors because they comprise nearly 30% of the entire cancer survivor population in the US and are the two most prevalent cancers in men and women.

METHODS: The first paper was a cross-sectional study using structural equation modeling to assess hypothesized pathways linking SCPs to survivor-level outcomes among a nationally representative sample of colorectal and breast cancer survivors from the Health Information National Trends Survey (HINTS). The second paper involved semi-structured interviews with safety-net breast and colorectal cancer survivors to elucidate the experiences with and

relevant outcomes of survivorship care planning. The third paper used an adapted-mixed methods approach to provide a high-level synthesis of relevant survivor-level outcomes.

RESULTS: The first paper found no total or direct effects linking the receipt of a SCP to survivor-level outcomes. Paper two found that the participants reported positive experiences with the survivorship care planning process and stated that their oncology care team prepared them for life post-treatment. The third paper modified a conceptual framework for survivorship care planning research by emphasizing the role of communication and distinguishing outcomes specific to the care planning process versus outcomes that likely require a survivor-level intervention.

CONCLUSION: These findings emphasize the central role of patient-centered communication in the survivorship care planning process and identified survivor-level characteristics and determinants that are likely to impact outcomes across the survivorship continuum.

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BACKGROUND

There are 15.5 million cancer survivors in the US living with the physical, cognitive, psychosocial, and socioeconomic issues that result from cancer and its treatment, and this number is expected to increase by 31% (20.3 million) by 2026 as the population ages and survival rates improve.¹⁻³ Breast and colorectal cancer survivors comprise approximately 30% of the total cancer survivor population and represent two of the most prevalent cancers in males and females.⁴ Breast cancer is the most common cancer among women with an estimated 3.5 million breast cancer survivors living in the US.⁴ More than 2.6 million breast cancer survivors are older than 60 years, while 7% are younger than 50 years.⁴ Due to improvements in detection and treatment, overall 5-year relative survival rates for female patients with breast cancer continues to increase and is currently 91%.^{5,6} Colorectal cancer is the fourth most common cancer diagnosis in the US, the third most common cancer among men and women, and the second most common cause of cancer death in the US.⁵ An estimated 1.5 million colorectal cancer survivors currently living in the US with 85% aged 60 years and older.⁴ The 5-year relative survival rates for colorectal cancer at 65% with higher rates seen with localized disease states.

Despite improvements in survival rates, disparities exist with older age, low income, low socioeconomic status, the presence of comorbidities, advanced stage, and poor tumor grades being associated with lower survival or higher mortality.^{7,8} Studies have shown that African American women are less likely to be diagnosed with local stage breast cancer compared to white women and African Americans have the highest colorectal cancer mortality rates of any racial or ethnic group.⁹ These racial disparities are primarily driven by socioeconomic factors, differences in comorbidities, less access to and use of high-quality medical care, and

biological differences in cancers.⁹⁻¹¹ Furthermore, older cancer survivors are more likely to have multiple chronic conditions and tend to experience decreased physical functioning compared to younger survivors.¹² Multiple chronic conditions and functional decline are concerning given that an estimated 66.7% of all cancer survivors will be 65 years of age or older by 2020.¹³ Finally, high-risk populations, such as under- or uninsured populations served by safety-net settings, also have higher overall burden of cancer and high prevalence of behavioral and psychosocial risk factors, making survivorship care especially important.¹⁴

Statement of the Problem

The landmark 2006 Institute of Medicine's (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*, identified cancer survivorship care as critical to the long-term health of cancer survivors.² Cancer survivors have complex journeys and are at increased risk for poor health outcomes, cancer recurrence, and the development of comorbidities that contribute to increased mortality rates.^{1,15,16} Cancer survivors must also engage in medical follow-up care in a fragmented health care system that is ill-prepared to meet the individual needs, preferences, and values of patients. As a result, survivors are not prepared for life after treatment due to a lack of information about the long-term side effects of treatment, follow-up care and surveillance, lifestyle recommendations to stay healthy, or details related to emotional and social support.¹⁷⁻²¹ Financial, legal, and other logistical challenges exist as well.^{2,22,23}

The ongoing growth in the number of survivors who are living longer after cancer coupled with the complexities of cancer survivorship has generated increased attention from leading health organizations to optimize survivorship care.²⁴⁻²⁶ To assist with this transition, the IOM embraces four components of survivorship care: 1) Prevention and detection of new

cancers and recurrent cancer; 2) Surveillance for recurrence of new primary cancers; 3) Interventions for long-term and late effects from cancer; and 4) Coordination between specialists and primary care providers to ensure that all survivors needs are met.²

Literature Review

Survivorship Care Plans

A key recommendation from the IOM report stipulates that cancer care providers develop and deliver to survivors' and their primary care providers survivorship care plans (SCPs).² SCPs are personalized documents that include plans for follow-up care (both self-maintenance and care received by healthcare providers), surveillance and prevention services, supporting information about the survivors' diagnosis, stage, and personalized summary of treatments received. Survivors can also learn about health-promoting behaviors, seek appropriate medical and psychological care, and learn about other relevant resources from SCPs. SCPs are intended to facilitate communication and care coordination among survivors, cancer care providers, and primary care providers resulting in improved health outcomes.² In the years following the release of the IOM report, several high-profile organizations, including the American College of Surgeons²⁷, the American Cancer Society²⁸, and others^{25,29,30} have recommended or mandated the use of SCPs to support the delivery of patient-centered care by addressing the complex needs of a growing cancer survivor population and improve health and healthcare outcomes.

Despite endorsements and mandates, SCP implementation has not been widespread across health systems with mixed evidence supporting the effectiveness of SCPs to improve health outcomes.³¹⁻³³ Although findings from observational studies have demonstrated

positive outcomes of SCPs for survivors, including satisfaction with care ³⁴, improved patient-provider communication ^{35,36}, increased confidence in one's ability to manage care ³⁷, and has been linked to changes in health behaviors, ³⁸ findings from RCTs conducted on SCPs show no effect on survivor-level outcomes.^{39,40} Null findings from RCTs may be partially explained by a lack of specificity of SCP content and studies largely focusing on process-based proximal outcomes including survivor knowledge and satisfaction with care, which may not be appropriate primary outcomes for measuring the impact of SCPs.^{32,41-43} Studies are also limited in capturing potential long-term improvements in survivor-level outcomes, and the types of information collected to assess survivorship programs vary greatly.³² There is a need to look beyond SCP delivery and examine proximal and distal outcomes of SCP receipt to better understand how to evaluate and improve SCP development and implementation.⁴⁴

As outlined in Table 1, there is potential for SCPs to positively affect outcomes at the survivor-level. Proposed outcomes of particular focus for future research include patient-provider communication, patient engagement through enhanced self-efficacy, lifestyle behaviors, and overall health.⁴⁵⁻⁴⁷ Importantly, outcomes should be patient-centered, capturing the most relevant health effects and other consequences.^{32,41,44} Being patient-centered requires an understanding of outcomes important to cancer survivors and understanding whether survivors feel that care plans render them prepared to manage their health and navigate their care in ways consistent with their needs and preferences. Furthermore, it is important that outcomes evaluating SCPs consider the perspectives of vulnerable populations that carry a disproportionate burden of cancer and its long-term effects. Therefore, future studies should consider and describe the unique and complex

characteristics of patients that are relevant to outcomes using qualitative methods. A better understanding of the complex relationships among SCPs and survivor-level outcomes may be used to inform survey instruments to assess relevant of potential outcomes in diverse populations and setting and help program strategically implement a well-defined intervention according to a plan that addresses key survivor-level outcomes.

Table 1. Evaluating Impact of Survivorship Care Plans: Metrics for Success

- Improved (perceived) patient-physician communication
 - Improved understanding of needed follow-up tests, their purpose and timing, and who will conduct them
 - Better understanding of potential late effects of illness and what symptoms might be important to report
 - Better adherence to recommended follow-up activities; fewer requests for unnecessary tests
 - Improved ability to identify providers and resources to address persistent effects of cancer and its treatment
 - Decreased cancer-related morbidity
 - Improved health-related quality of life and function
 - Improved healthy lifestyle choices
 - Potentially improved overall survival
-

NOTE: Table Adapted.⁴⁸

Survivor-Level Outcomes

Patient-Centered Communication

The 2013 IOM report, *Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis*, emphasized that care be patient-centered to meet the needs of a cancer care delivery systems facing increased complexity and barriers to quality.⁴⁹

Recommendations for SCPs explicitly state that patient-centered care should be promoted among cancer survivors and that communication between patients and providers is central to delivering high-quality survivorship care.⁵⁰ The National Cancer Institute (NCI) monograph Patient-Centered Communication (PCC) in Cancer Care recognized the importance of communication in cancer care and outlines six core functions essential for meeting the complex needs of cancer survivors: 1) Fostering healing relationships; 2) Exchanging

information; 3) Responding to emotions; 4) Managing uncertainty; 5) Making decisions; and 6) Enabling patient self-management.⁵¹

The importance of communication as a means of achieving the best health outcomes for patients is further underscored by the IOM report, *Crossing the Quality Chasm*, which identifies “patient-centeredness” as key to improving health through continuous healing relationships.⁵² High-quality patient-provider communication is central to patient-centered care and requires interactive communication where there is an active effort toward communicating and understanding concerns and goals of care and where participation in the process is reciprocated between patient and clinician.

Not only is PCC central to delivering high-quality cancer care, but studies have also established a direct and indirect pathways between PCC and patient health outcomes.^{51,53-55} Direct pathways may result from physician’s expressing empathy that may result in fewer negative emotions and more positive ones.^{56,57} In most cases, PCC affects health through indirect or mediated routes through proximal outcomes (e.g., self-efficacy to manage health) that could, in turn, affect health or that could contribute to the intermediate outcomes (e.g., adherence to lifestyle behaviors) that lead to better health.^{51,53}

Unfortunately, the quality of PCC in cancer survivorship is suboptimal with gaps in the communication quality most notable among survivors with multiple chronic conditions and racial/ethnic minorities.⁴³⁻⁴⁵ These gaps in communication often result in confusion, insecurity, a sense of abandonment among survivors.^{58,59} Poor communication between patients and providers can have negative consequences including decreased satisfaction with care, lower rates of cancer screening, and disparities in cancer care.⁵⁵ Previous studies reported differences in perceived patient-provider communication quality by socio-

demographics (age, race, health literacy) and other factors including depressive symptoms, health care access, trust, and disease-related factors.^{17,60-63}

Health Self-Efficacy

As the focus of cancer care and control efforts shifts towards more personalized and long-term approaches, empowering cancer survivors to assume a more active role in their own health care is becoming an increasingly essential component of cancer survivorship.^{64,65} SCPs may be a tool for increasing a survivors ability to self-manage.² Self-management in cancer survivorship involves managing consequences of cancer and its treatment, understanding how and when to seek support, recognizing and reporting signs and symptoms, and adhering to lifestyle and clinical recommendations that promote survival.⁶⁶ Central to survivors' success in self-management is health self-efficacy or their confidence in their ability to manage the health and healthcare consequences of cancer and its treatment.^{67,68}

Self-efficacy is a direct and proximal determinant of behavior change and is most predictive of behavioral outcomes.⁶⁹⁻⁷¹ Self-efficacy is a highly specific behavior that influences one's choice of activities, how long one will persevere when faced with a challenge, and the ability to cope or handle situations that are high stress.⁶⁹ Patients with higher self-efficacy for disease management have confidence in their ability to manage symptoms, treatment, and physical consequences of their condition, as well as their ability to make behavioral, cognitive, and emotional changes needed to maintain quality of life and overall health.⁷² Indeed, self-efficacy has been associated with emotional well-being, coping, and adherence to lifestyle, surveillance, and follow-up behaviors in cancer survivorship.^{64,66,73} It is, therefore, a common target of many self-management interventions.

Lifestyle Behaviors

There is compelling evidence linking lifestyle behaviors to health outcomes in cancer survivors. Engaging in healthy lifestyle behaviors has been shown to mitigate cancer-related effects, decrease the risk of comorbidities, reduce cancer recurrence, and improve 5-year mortality rates.⁷⁴ Furthermore, cancer survivors require regular follow up with their primary care provider to adhere to age-appropriate screening, cancer screening, and other preventive measures important for the long-term health of cancer survivors.⁷⁵ A core component of SCPs is to emphasize preventive practices and recommendations for healthy living after cancer treatment. Yet, the focus of follow-up care is overwhelmingly on cancer surveillance, leaving other important healthy lifestyle behaviors relatively unaddressed.²¹ Studies have also shown that only 39% of cancer survivors report that a provider ever discussed lifestyle recommendations and 32% and 12% of oncologists and primary care providers respectively report always discussing lifestyle recommendations for survivorship care with patients.^{17,76,77}

In order to inform and facilitate physician recommendations for cancer survivors engagement in health behaviors, several lead health agencies, including the National Comprehensive Care Network (NCCN), provided cancer survivor-specific health lifestyle guidelines (Table 2).⁷⁸ Survivors who follow these guidelines experience significant health benefits and improved quality of life.

Table 2. NCCN Healthy Lifestyle Guidelines

- Engage in at least 150 minutes of moderate-vigorous physical activity or 75 minutes of vigorous activity per week
 - Engage in 2 to 3 sessions per week of strength training
 - Eat a minimum of 5 servings of fruit and vegetables a day
 - Avoid or stop the use of tobacco products
 - Visit a primary care provider annually
-

Yet, the majority of cancer survivors fail to meet these lifestyle guidelines. It is estimated that 70% of cancer survivors are overweight or obese with subsequent weight gain following active treatment.^{79,80} Approximately 66% to 70% of cancer survivors do not meet the physical activity guidelines, 20% to 50% are not meeting nutritional guidelines, 15% to 24% continue to smoke, and approximately 23% of cancer survivors attend fewer than the recommended number of office visits with declines seen over time.⁸¹⁻⁸³ Moreover, survivors are less likely to receive general preventive health care compared to those without a cancer diagnosis.⁸⁴ Disparities in adherence to guidelines are seen across racial/ethnic, uninsured, and underinsured survivors.⁸⁵

Summary

Cancer survivors will continue to experience significant challenges following the completion of active treatment, such as suboptimal communication, challenges managing cancer-related issues and overall health, adherence to lifestyle behaviors, and provision of preventive care, critical for quality of life and overall survival. SCPs may be useful tools for addressing these challenges; however, major questions regarding pathways linking SCPs to appropriate survivor-level outcomes remain that impact how cancer care programs measure the effectiveness of SCPs. To address limitations in measuring the effectiveness of SCPs, researchers have called for studies of SCPs to identify outcomes more congruent with SCP intervention content and targets.⁸⁶

Public Health Significance

Significantly more work is needed to identify and refine the most relevant survivor-level outcomes to be measured in studies examining SCPs, notably with more diverse samples with characteristics that reflect the diversity found in practice. Previous studies have

examined relationships between SCPs and outcomes but most evaluated process-based outcomes, such as knowledge and satisfaction and did not utilize a comprehensive framework included proximal and distal survivor-level outcomes of SCPs.^{40,42,44} Without a comprehensive framework, inconsistencies in results and null findings are likely to persist. Parry et al., proposed a conceptual framework through which SCPs may impact health outcomes, but no study has empirically tested the proposed pathways using a representative sample of colorectal and breast cancer survivors and compared results to underserved cancer survivors within a safety-net setting.⁴⁴ In fact, few survivorship studies include under- and uninsured patient populations who bear a disproportionate burden of cancer and have the most challenges following the completion of active treatment. Moreover, there is a lack of underrepresented populations included in health research overall, and may also be less represented in outcome studies related to SCPs.

Findings from this study will address a critical gap in the literature regarding the fundamental pathways linking SCPs to survivor-level outcomes. Furthermore, understanding the first-hand experiences of safety-net cancer survivor populations with SCPs and survivorship care overall is critical to the determination of the most salient survivor-level outcomes that aligns with their needs and priorities, and may help to refine current frameworks around SCPs. This study will build upon the existing evidence linking SCPs to proximal and distal survivor-level outcomes that can help inform the development of a patient-reported outcome measure that cancer care programs can use to measure the effectiveness of SCPs on relevant outcomes that considers the diverse populations and settings in which SCPs are delivered. Finally, findings from this study may assist cancer care

programs to strategically implement a well-defined SCP intervention according to a plan that addresses key survivor-level outcomes.

Specific Aims or Objectives

The objective of this dissertation research is to understand the complex relationship between receipt of a SCP with survivor-level outcomes among colorectal and breast cancer survivors. This proposal involves primary and secondary data collection and qualitative and quantitative methods. The overall aims of this dissertation research are as follows: (1) assess the direct and indirect relationship between SCPs, proximal, and distal outcomes among breast and colorectal cancer survivors using data from the Health Information National Trends Survey (HINTS), (2) elucidate patient's experience with and relevant outcomes of survivorship care planning through analysis of semi-structured interviews with vulnerable breast and colorectal cancer survivors from NCI R01CA203856- Project CONNECT at Parkland Health and Hospital System (Parkland), and (3) characterize relevant survivor-level outcomes at a patient and population level among breast and colorectal cancer survivors using an adapted mixed methods approach. This dissertation includes three papers that correspond to the three overall aims of this dissertation research:

Paper 1: Cross-sectional study assessing the hypothesized relationships between SCPs and survivor-level outcomes among a nationally representative sample of colorectal and breast cancer survivors.

Aim 1: Characterize the prevalence of receipt of an SCP, proximal, and distal outcomes among colorectal and breast cancer survivors.

Aim 2: Test the measurement model for lifestyle behaviors and physical health using confirmatory factor analysis (CFA).

Aim 3: Determine overall model fit of a conceptual framework postulating relationships between receipt of SCP, proximal, and distal outcomes.

Aim 4: Identify direct and indirect pathways linking receipt of care plan to proximal and distal outcomes.

Paper 2: A qualitative study elucidating the experiences with and relevant outcomes of survivorship care planning among safety-net colorectal and breast cancer survivors.

Aim 1: Describe experience with survivorship and SCPs among safety-net colorectal and breast cancer survivors at Parkland.

Aim 2: Characterize relevant survivor-level outcomes of survivorship care among safety-net colorectal and breast cancer survivors at Parkland.

Aim 3: Compare and contrast relevant survivor-level outcomes by cancer site among safety-net colorectal and breast cancer survivors at Parkland.

Paper 3: Uses an adapted mixed methods approach to synthesize relevant survivor-level outcomes at a patient and population level among breast and colorectal cancer survivors.

Aim 1: Compare and contrast quantitative and qualitative findings from papers one and two,

Aim 2: Refine existing survivorship care planning frameworks.

Aim 3: Suggest future directions and recommendations around the importance of understanding survivor-level outcomes.

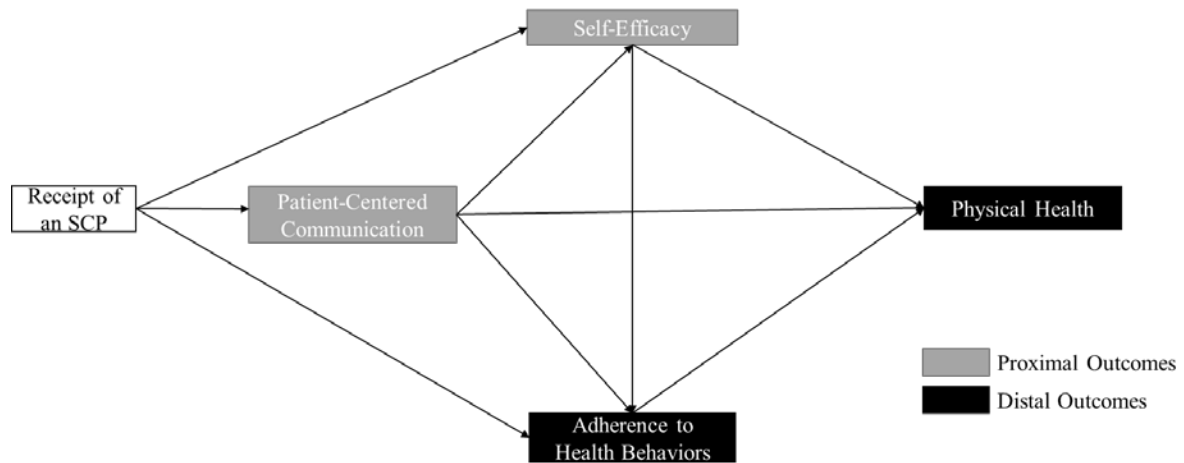
Conceptual Framework

Few frameworks clearly depict the proposed pathways linking SCPs to proximal and distal survivor-level outcomes. The seminal IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition*, provided a clinical framework of SCPs and outlined four

essential components of cancer survivorship that may affect survivor-level outcomes, such as patient-centered communication (PCC).² Parry et al. proposed a clinical framework based off the landmark IOM report in which SCPs facilitate patient-provider communication, in turn, resulting in improvements in survivor-level outcomes, such as management of late effects, and long term physiological and psychosocial outcomes.⁴⁴ However, the framework does not define indirect effects of SCPs on survivor-level outcomes. Recommendations for SCPs also explicitly state that communication between patients and providers, or patient-centered communication (PCC), is central to delivering high-quality survivorship care.⁵⁰ PCC is suggested to be an important proximal outcome of SCPs that may impact long-term health directly or indirectly via proximal (health self-efficacy) and intermediate outcomes (adherence to lifestyle behaviors).^{51,63} Lafata et al. proposed a conceptual framework in which the communication exchange between the patient and the provider itself can directly lead to improved health outcomes during and after cancer. Yet, in most cases, communication likely affects health outcomes indirectly through affective-cognitive outcomes, such as health self-efficacy, and behavioral outcomes, such as exercise and nutrition.^{63,86}

The **conceptual framework guiding this dissertation** adapts Parry et al. model of Survivorship Care Planning Research with Lafata et al. model of Patient-Clinician Communication and clearing depicts the direct and indirect pathways through which SCPs may impact proximal and distal health outcomes (Figure 1).

Figure 1. Conceptual Framework depicting hypothesized pathways linking SCPs to survivor-level outcomes.



METHODS PAPER 1

Paper 1 assesses the hypothesized relationships between SCPs and survivor-level outcomes among a nationally representative sample of colorectal and breast cancer survivors from the Health Information National Trends Survey (HINTS). Informed by the conceptual framework, SEM techniques will be used to examine overall model fit of conceptual relationships and identify direct and indirect pathways linking receipt of treatment summaries, a proxy for SCPs, to proximal and distal survivor-level outcomes.

Data Source and Sample

The HINTS is a nationally representative probability survey funded by the NCI designed to assess current access to and use of information about cancer across the cancer care continuum from cancer prevention, early detection, diagnosis, treatment, and survivorship.⁸⁷ We combined data from two iterations of HINTS: HINTS 4, Cycle 4 (fielded August-November, 2014, response rate 34.4%), and HINTS 5, Cycle 1 (fielded January-May, 2017, response rate 32.4%). These iterations were selected due to their proximity to the Commission on Cancer (CoC) 2015 mandate for SCP delivery and are the only two surveys that include all outcomes of interest following the release of the IOM report. Information on the two-stage stratified sampling design and other methodological details are described on the HINTS website (<https://hints.cancer.gov/data/survey-instruments.aspx>). For the analysis, we restricted the sample to those who reported a personal history of colorectal or breast cancer. We excluded those who never received treatment for their cancer or were still in active treatment since these individuals would not be expected to have received an SCP.

Survey Items

Appendix A provides a list of relevant HINTS survey items, responses for each item of interest, and analytic categories. The primary predictor variable in the model is the receipt of an SCP. Survey items representing PCC, health self-efficacy, and a latent measure of adherence to health behaviors will serve as both predictor and outcome variables in the model. The primary outcome variable is a latent measure of self-reported physical health.

Receipt of an SCP: Respondents answered the following questions: *“Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatment you received for your cancer?”* Response options were yes or no. This item has previously been used as a proxy for SCPs and treatment summaries.⁸⁸

Patient-Centered Communication: Respondents were asked six questions corresponding to the six functions of PCC and overlapping concepts. However, the item representing fostering healing relationships was not included in the HINTS 5, Cycle 1 iteration. To address this limitation, the six items consistent across all iteration were reviewed and a Cronbach’s alpha was obtained comparing the initial set of six HINTS PCC items used in previous studies to the revised set PCC items proposed for this analysis using the HINTS 4, Cycle 4 sample. Results indicated strong reliability of the new items ($\alpha = 0.93$) similar to the initial set of items ($\alpha = 0.92$). Therefore, the following items will be included in the analysis: *How often did the doctors, nurses, or other health care professional you saw during the past 12 months do each of the following: (1) Give you a chance to ask all the health related questions you had?* (reflecting Fostering Healing Relationships) *(2) Give the attention you needed to your feelings and emotions?* (Responding to emotions) *(3) Involve you in decisions about your health care as much as you wanted?* (Making

decisions) (4) *Make sure you understood the things you needed to do to take care of your health?* (Enabling self-management) (5) *Explain things in a way you could understand?* (Exchanging Information) (6) *Help you deal with feelings of uncertainty about your health or healthcare?* (Managing uncertainty). Response options were always, usually, sometimes or never. Following previous approaches, items were reversed scored prior to analysis and an overall PCC score was created, where higher scores indicate higher levels of PCC.⁸⁹⁻⁹¹

Health Self-Efficacy: Respondents were asked to rate their confidence in their ability to take care of their health. Response options were completely confident, very confident, somewhat confident, a little confident, and not confident at all. Consistent with previous item use, items were reversed score prior to analysis and summed to create a continuous overall score for health self-efficacy with higher scores indicating greater levels of self-efficacy to manage health.⁹²

Health Behaviors: Evidence supports combining health behaviors that are health enhancing into a latent variable since there is a tendency for these behaviors to co-occur.^{93,94} Respondents provided information on healthy lifestyle behaviors including aerobic physical activity, fruit and vegetable intake, and tobacco use. Responses were categorized to align with NCCN recommended guidelines (see Appendix A) and loaded onto a single categorical latent variable.⁹⁵

Physical Health: Evidence supports the creation of a latent measure for physical health by combining BMI, number of comorbidities, and subjective self-ratings of health.⁹⁶ BMI was derived using self-report height and weight. Respondents were asked to indicate yes/no to ever being told if they had each of the following conditions: diabetes or high

blood sugar, hypertension or high blood pressure, a heart condition, chronic lung disease, or arthritis or rheumatism. To calculate the number of chronic conditions, responses were summed with higher scores indicating a higher number of chronic conditions. Finally, respondents were also asked to rate their overall health with response options being excellent, very good, good, fair, and poor. Responses were reversed scored with high scores indicating better overall health.

Statistical Analysis

Prior to the analysis, we performed all necessary data management and screening procedures including merging of data sets, creation of new variables, assessment of normality, linearity, missing data, and outliers using SAS 9.4 (SAS Institute Inc., Cary, NC, USA). To reduce the risk of a Type 1 error, we incorporated HINTS-supplied survey weights using jackknife variance estimation techniques into inferential analyses to account for the complex HINTS sampling design and to calculate nationally representative estimates.⁹⁷ All analyses were performed again removing replicate weights but maintaining survey weights as there is debate concerning the added utility that replicate weights bring to the following analysis.

Despite efforts to improve the completeness of data collection, missing data in the HINTS dataset is not uncommon and can result in a reduction in sample size and possible bias. Prior to analysis, we assessed the percentage of missing data and the pattern of missing data. There are two techniques for addressing missing data for this analysis; maximum likelihood (ML) and multiple imputation. ML is the default in most structural equation modeling software's and uses all observable data to estimate the missing portions of a variable. However, ML is impractical unless the data contain only a few distinct patterns of

missing data and assumes multivariate normality. If the fraction of missing data is greater than 10 percent, multiple imputation techniques prior to analysis will be performed. Multiple imputation replaces each missing item in the dataset with an imputed value, and then analyzes the dataset as if it were complete. The advantage of multiple imputation is that it increases the efficiency in estimation and the ability to incorporate information in an effort to reduce nonresponse bias.⁹⁸

This analysis includes descriptive statistics of the sample including demographic, clinical, and cancer-related information, gender, age, education, race, income, health insurance, and cancer site. We used structural equation modeling (SEM) using MPlus Editor 7 (Los Angeles, CA: Muthén & Muthén) to test the direct and indirect effects between SCPs, proximal, and distal outcomes. SEM is a multivariate statistical analysis technique that combines factor analysis and multiple regression analysis to analyze the structural relationships between measured variables and latent constructs. There are two types of models specified in SEM – the measurement model and the structural model. The measurement model represents how measured variables come together, or the creation of latent variables, while the structural model represents how constructs are related to other construct and tests the proposed relationships between variables.

We calculated descriptive statistics including means/frequencies and percent/standard deviations of relevant outcomes identified in our conceptual framework and used Confirmatory Factor Analysis (CFA) to validate the measurement portion of the model (latent structure of health behaviors and physical health) using a robust estimator based on the normality of the data. Empirical evidence supports the creation of a one-factor reflective

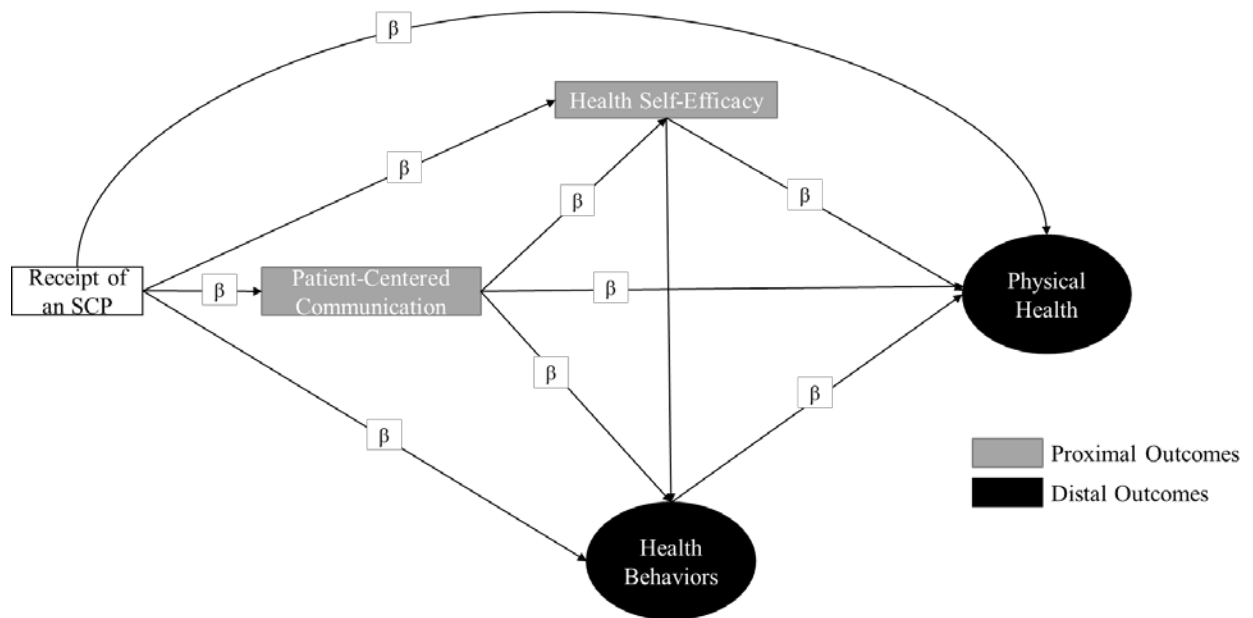
model for both health behaviors and physical health. To identify each latent model, we fixed the first item loading onto the latent factor to one.

We assessed overall model fit using chi-square goodness-of-fit test, comparative fit index (CFI), the root mean square error of approximation (RMSEA), and weighted root mean square residual (WRMR).⁹⁹⁻¹⁰¹ Examination of RMSEA values below 0.10, CFI values above 0.95, and WRMR values below 1.0 suggest approximate model fit. We examined modification indices, standardized factor loadings, and residuals to assess localized areas of ill fit. Based on fit diagnostic information and substantive justification, the model may be revised to fit the data to improve the goodness of fit. An indicator being specified to load onto a latent factor based on previous research may have no salient relationship to the factor. In this instance, the indicator may be dropped from the model and examined as a manifest variable. We also examined the correlations between indicators to detect problematic discriminant validity using guidelines for multicollinearity in regression (correlation ≥ 0.85). If indicators overlap to this degree, factors may be combined or dropped to acquire a more parsimonious solution if supported by a clear rationale. In the event that neither latent structure shows a good fit to the data, a subset of indicators will be retained based off localized fit indices, discriminant validity, and justification within the literature.

Following the CFA, we tested the hypothesized structural model of both latent and observed variables using a robust estimator. The model included both continuous and categorical variables. All variables were assessed for normality based on skewness and kurtosis. Figure 2 presents the a priori set of hypothesized direct and indirect relationships between variables and the final structural model. The latent variables are depicted as ovals and observed variables are in rectangles. The adequacy of the structural model will be tested

using the chi-square goodness-of-fit test, CFI, RMSEA, and WRMR. We obtained standardized parameter estimates representing direct and indirect effects with the significance level set to 0.05.

Figure 2. Hypothesized pathways linking SCPs to Proximal and Distal Outcomes



METHODS PAPER 2

Paper 2 *elucidates safety-net breast and colorectal cancer survivors' experience with and relevant outcomes of survivorship care planning* through the analysis of semi-structured interviews and builds upon the parent study NCI R01CA203856- Project CONNECT at Parkland Health and Hospital System (Parkland). Project CONNECT is a quasi-experimental hybrid implementation-effectiveness study aimed at adapting, implementing, and evaluating three evidence-based care coordination strategies among vulnerable breast and colorectal cancer survivors with multiple comorbidities receiving care at Parkland.

Aim 1: Describe experience with survivorship and SCPs among safety-net colorectal and breast cancer survivors at Parkland.

Aim 2: Characterize relevant survivor-level outcomes of survivorship care among safety-net colorectal and breast cancer survivors at Parkland.

Aim 3: Compare and contrast relevant survivor-level outcomes by cancer site among safety-net colorectal and breast cancer survivors at Parkland.

Setting

This study captured under- and uninsured populations at Parkland – the sole integrated safety-net provider for approximately one million under- and un-insured Dallas County residents living at < 200% poverty level in Texas. Safety-net providers serve patients regardless of their ability to pay, whose patient mix includes substantial numbers of uninsured, Medicaid, and other disparate populations.¹⁰² Breast and colorectal are two of the most prevalent cancers treated at Parkland with approximately 250 new cases diagnosed each year. The Parkland cancer program is accredited by the *American College of Surgeons Commission on Cancer*, thus mandated to provide all survivors with an SCP, making them an

ideal population for understanding experiences with survivorship care planning. Preliminary data from Project CONNECT suggests that SCP delivery is limited and providers' experience challenges communicating details of survivorship care to patients, particularly among low-income, racial/ethnic minority survivors struggling with multiple chronic conditions.

Patient Sample and Recruitment

Using electronic health record data and registry data, we identified patients diagnosed with stage I, II, and III breast or colorectal cancer who completed active treatment in the last 18 months and were enrolled in Project CONNECT. We defined the completion of active treatment as the completion of initial surgical treatment and/or initial adjuvant chemotherapy and radiation. Those with in situ (stage 0) and metastatic disease (stage IV) were excluded because they are unlikely to receive a SCP. Those with impaired hearing or speech and/or the inability to comprehend or speak English, were also excluded from participation.

A non-proportional quota sample was chosen from eligible participants who expressed an interest in taking part in an interview with the research team. The research staff aimed to recruit a diverse sample of survivors to examine potential differences in post-treatment experiences and outcomes by cancer site (50% Breast, 50% Colorectal). Participants were selected to populate the cancer site subgroup with the aim of recruiting a maximum of 10 participants who completed treatment in the last 18 months. Up to 6 attempts (day, evening, weekend) were made to reach eligible participants. All interviews acquired informed consent and were performed using a semi-structured interview guide by a trained member of the research staff. Interviews were audio-recorded and participants were compensated \$20 for their time.

Patient Telephone interviews

Prior experience with Parkland cancer patients shows that patient are able and willing to complete phone interviews. Each telephone interview lasted approximately 30-45 minutes. The semi-structure interview guide was informed by the conceptual framework and focused on the participants experience with survivorship care planning and their experience following the care planning visit. We asked participants to reflect on their last treatment visit with their oncology care team to understand their experiences with survivorship care planning. Specifically, we asked the participants to recall the information they received and discussed with their oncology care team during their last treatment visit. To elucidate potential outcomes of survivorship care more broadly, we asked participants to describe their post-treatment experience. We probed participants to discuss how they knew they were doing well post-treatment and to identify the most important thing they could do to stay healthy after cancer treatment. See Appendix B for the final interview guide.

Data Collection and Analysis

All data was professionally transcribed, de-identified, and analyzed in NVivo (QSR, International, AUS). Two members of the research team performed thematic content analysis using a deductive-inductive approach.¹⁰³ Each transcript was reviewed in its entirety without coding to allow themes and subthemes to emerge. Then, drawing on constructs from our conceptual model, we developed a deductive code structure that was applied to a random selection of transcript during an initial open coding session.^{104,105} As new ideas emerged, the research team considered inductive themes and domains, allowing the codebook to evolve.^{104,105} The revised codebook was then applied to the remaining transcripts. The team coded the transcripts independently before coming together to compare codes. All

discrepancies in codes were resolved through consensus and analysis continued until no new ideas emerge from subsequent interviews and resulting themes were deemed saturated.¹⁰⁶

METHODS PAPER 3

Paper 3 integrates findings from papers one and two to provide a high level synthesis of relevant survivor-level outcomes among breast and colorectal cancer survivors using an adapted mixed methods approach.

Aim 1: Compare and contrast findings from paper two with results from a subset of breast and colorectal cancer survivors from paper one.

Aim 2: Refine conceptual framework informed by existing frameworks of SCPs.

Aim 3: Suggest future directions and recommendations around the importance of understanding survivor-level outcomes.

Data Collection and Analysis

The quantitative and qualitative data from papers one and two were analyzed separately and integrated for final analysis (see Appendix C). Due to differences in the sample composition between the two data sources, we pulled an additional subset of colorectal and breast cancer survivors from the initial quantitative HINTS dataset to be more similar to the qualitative interview sample. The new subset of breast and colorectal cancer survivors was limited to non-Hispanic (NH) white and black women only with at least two chronic conditions who completed treatment in the last five years. We calculated descriptive statistics including weighted means/frequencies and percent/standard deviations of the HINTS survey items representing the outcomes identified in our conceptual framework (i.e., receipt of an SCP, health self-efficacy, PCC, health behaviors, and physical health) across both samples. All analyses incorporated the HINTS supplied survey weights to calculate nationally representative estimates.

Interpretation and reporting of data followed a narrative approach.^{107,108} Results were triangulated and connected to each other thematically, and the qualitative and quantitative data weave back and forth around similar themes or concepts (see Appendix C).¹⁰⁸ The narrative approach provides intragroup comparisons of the results from the quantitative data that are either supported or challenged by text from the qualitative database.¹⁰⁹ For example, if the proportion of survivors receiving a care plan was low at a population level, the qualitative results may assist in identifying barriers at Parkland that can serve as a point of intervention (hypothesis-generating). Themes focused on outcomes informed by the conceptual framework. Finally, the analytic team reviewed all data with special attention to narrowing the broader conceptual framework driving this study to include only the specific components confirmed following integration and their possible causal linkages of interest.¹¹⁰

JOURNAL ARTICLE 1

Working Title: A Structural Equation Modeling Approach to Understanding Pathways Linking Survivorship Care Plans to Survivor-level Outcomes.

Name of Journal Proposed for Article Submission: Journal of Cancer Survivorship

Introduction

Following the completion of active cancer treatment, cancer survivors remain at increased risk for poor health outcomes, cancer recurrence, and the development of chronic conditions that contribute to increased mortality rates.¹⁻³ In the years following the release of the landmark Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*, several high-profile organizations, including the American College of Surgeons⁴, the American Cancer Society⁵, and others⁶⁻⁸ have recommended or mandated the use of survivorship care plans (SCPs) to address the complex needs of a growing cancer survivor population. SCPs are tailored documents that combine personalized treatment summaries with plans for follow-up care, surveillance, preventions, and supporting information around health-promoting behaviors.⁹ SCPs are intended to facilitate communication among survivors and clinical care teams, resulting in improved health outcomes.^{9,10}

Evidence regarding the effectiveness of SCPs on health and healthcare outcomes remains mixed due to inconsistencies across studies in the selection of outcomes for measuring SCP effectiveness.¹¹⁻¹³ As a result, researchers have advocated for studies that identify the most appropriate outcomes of SCP receipt, particularly at the survivor-level. Findings from observational studies show that SCPs have the ability to impact both proximal

and distal survivor-level outcomes including patient-provider communication,^{14,15} increased confidence in one's ability to manage care,¹⁶ changes in health behaviors, and improvements in overall health.¹⁷ However, a recent systematic review found that many randomized controlled trials of SCP delivery on patient-reported health status and perceptions of care yielded statistically non-significant findings.¹³ Among the few studies with significant findings, results suggest that SCPs are more likely to impact proximal outcomes including knowledge and satisfaction with care.^{12,18-22}

Without a comprehensive framework for studying survivorship care planning, inconsistencies in measured outcomes are likely to persist, limiting the extent to which definitive conclusions can be drawn about the impact of SCPs. Yet, few frameworks of survivorship care planning exist that depict the proposed pathways linking SCPs to survivor-level outcomes. Parry et al. proposed a clinical framework of Survivorship Care Planning in which SCPs facilitate communication that, in turn, influence later outcomes, such as management of late effects, and long term physiological and psychosocial outcomes.²³ However, the framework does not depict indirect pathways linking the delivery of SCPs to survivor-level outcomes. Recommendations for SCPs also explicitly state that communication between patients and providers, or patient-centered communication (PCC), is central to delivering high-quality survivorship care.²⁴ Lafata et al. proposed a conceptual framework in which the communication exchange between the patient and the provider itself can directly lead to improved health outcomes during and after cancer. Yet, in most cases, communication likely affects health outcomes indirectly through affective-cognitive outcomes, such as health self-efficacy, and behavioral outcomes, such as exercise and nutrition.^{25,26}

To date, few studies have utilized a comprehensive framework of survivorship care planning and the majority of studies that have identified direct pathways linking SCPs to various outcomes primarily control for sociodemographic, clinical, and cancer-related characteristics and have tested these pathways in a single cancer site. As a result, no study has simultaneously tested the direct and indirect pathways linking SCPs to survivor-level outcomes.^{23,27} Examining these proposed pathways simultaneously using structural equation modeling (SEM) in a representative sample of cancer survivors would address this gap by offering a more complete and comprehensive approach to understanding the impact of receiving a SCP on survivor-level outcomes.

Therefore, the objective of this study is to assess the direct and indirect relationships between the receipt of an SCP on proximal and distal survivor-level outcomes among a nationally representative sample of cancer survivors using data from the Health Information National Trends Survey (HINTS). Based on existing frameworks of survivorship care planning research and communication, this study attempts to identify outcomes of survivorship care planning at the survivor-level and test a hypothesized model postulating proposed pathways through which SCPs effect proximal and distal outcomes. We used an SEM approach to (1) test a measurement model for lifestyle behaviors and physical health using confirmatory factor analysis (CFA); (2) assess direct and indirect pathways linking receipt of SCP to proximal and distal outcomes; and (3) determine overall model fit of a conceptual framework postulating relationships between receipt of a SCP, proximal, and distal outcomes. To our knowledge, no study has examined the direct and indirect pathways linking SCPs to proximal and distal outcomes. Findings from this study will fill an important

gap in existing research on the most appropriate survivor-level outcomes for measuring SCP effectiveness and may help inform future models of survivorship care planning.

Methods

Survey Design and Sample

The Health Information National Trends Survey (HINTS) is a nationally representative cross-sectional probability survey administered in English and Spanish by the National Cancer Institute. Respondents complete a one-time survey to assess current access to and use of information about cancer across the cancer care continuum from cancer prevention, early detection, diagnosis, treatment, and survivorship. Information on the two-stage stratified sampling design and other methodological details are described on the HINTS website (<https://hints.cancer.gov/data/survey-instruments.aspx>).

We combined data from two iterations of HINTS: HINTS 4, Cycle 4 (fielded August-November, 2014, response rate 34.4%), and HINTS 5, Cycle 1 (fielded January-May, 2017, response rate 32.4%). These iterations were selected due to their proximity to the Commission on Cancer 2015 mandate for SCP delivery and are the only two surveys that include all outcomes of interest following the release of the IOM report. For this analysis, we restricted the sample to those who reported a personal history of breast or colorectal cancer and excluded those who indicated that they were still in active treatment – defined as still receiving chemotherapy, radiation, and/or surgery for their cancer - to align with the post-treatment phase of cancer survivorship.⁹ We chose breast and colorectal cancer survivors because they comprise approximately 30% of the total cancer survivor population and represent two of the most prevalent cancers in males and females.²⁸ The final sample size for the analysis was 212 cancer survivors.

Survey Items

Respondents reported sociodemographic, clinical, and cancer-related information, including gender, age, education, race, income, health insurance status, and cancer site. Appendix A provides a list of relevant HINTS survey items, responses for each item of interest, and analytic categories used in this analysis.

Receipt of SCP. The primary predictor variable in the model was receipt of an SCP.

Respondents answered the following questions: “*Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatment you received for your cancer?*” Response options were yes or no. This item has previously been used as a proxy for SCPs.²⁹

Patient-Centered Communication. Survivors were asked about their communication experiences during the prior 12 months with doctors, nurses, or other health professionals. These items were grounded in the PCC framework originally proposed by Epstein and Street, corresponding to the six core functions of PCC and overlapping concepts that impact the communication exchange.³⁰ Response options were always, usually, sometimes or never. Items were reverse scored prior to analysis and summed to create a continuous overall score for PCC, where higher scores indicate higher levels of PCC.^{31,32}

Health Self-Efficacy. Respondents were asked to rate their confidence in their ability to take care of their health. Response options were completely confident, very confident, somewhat confident, a little confident, and not confident at all. Items were reverse scored and treated as a continuous variable with higher scores indicating higher levels of self-efficacy to manage health.³³

Health Behaviors. Respondents provided information on healthy lifestyle behaviors, including aerobic physical activity, fruit and vegetable intake, and tobacco use.

Evidence supports combining health behaviors that are health-enhancing into a latent variable since there is a tendency for these behaviors to co-occur.^{34,35} Responses were categorized to align with the National Comprehensive Care Networks (NCCN) recommended guidelines and loaded onto a single latent variable.³⁶

Physical Health. Respondents provided information around their physical health, including their perceived health status, body mass index (BMI), and number of comorbidities. The HINTS survey includes a variable calculating BMI for all respondents who self-reported height and weight. To calculate the number of chronic conditions, respondents indicated yes/no to ever being told if they had each of the following conditions: diabetes or high blood sugar, hypertension or high blood pressure, a heart condition, chronic lung disease, or arthritis or rheumatism. Responses were summed with higher scores indicating a higher number of chronic conditions. Finally, respondents were also asked to rate their perceived overall health with response options being excellent, very good, good, fair, and poor. Responses were reverse scored with high scores indicating better overall health.

Data Analysis

We calculated descriptive statistics of the sample, including sociodemographic, clinical, and cancer-related information, including gender, age, education, race, income, health insurance, and cancer site. We also characterized the prevalence of receiving an SCP and provide descriptive statistics for survey items corresponding to the proximal and distal outcomes identified in our conceptual framework.

We used SEM to test whether our conceptual model was supported by the HINTS data. SEM is a multivariate statistical analysis technique that combines factor analysis and multiple regression analysis to analyze the structural relationships between measured variables and latent constructs. There are two types of models specified in SEM – the measurement model and the structural model. The measurement model represents how measured variables come together, or the creation of latent variables, while the structural model represents how constructs are related to other construct and tests the proposed relationships between variables. We developed and tested two latent variables for healthy lifestyle behaviors and physical health using confirmatory factor analysis (CFA) as described by Brown.³⁷ To accommodate the use of some categorical indicators and account for missing data, we estimated parameters using weighted least squares with robust standard errors (WLSMV). Parameters were therefore estimated in terms of linear regression coefficients for continuous indicators and by probit regression coefficients for categorical indicators (Muthén & Muthén).

After evaluating the fit and factor loadings of the measurement model, we specified an a priori structural model as proposed in Figure 1. The hypothesized structural model is based on Parry et al. clinical framework of Survivorship Care Planning in which SCPs facilitate communication, in turn, resulting in improved health outcomes.²³ We adapted Parry et al. framework to emphasize PCC by incorporating Lafata et al. conceptual framework in which the communication exchange between the patient and the provider itself can directly lead to improved health outcomes during and after cancer and, in most cases, affects health indirectly through health self-efficacy and healthy behaviors.^{25,26}

For the full structural model we obtained standardized parameter estimates representing direct and indirect effects with the significance level set to 0.05 using the WLSMV estimator. Overall model fit was assessed using chi-square, comparative fit index (CFI), the root mean square error of approximation (RMSEA), and weighted root mean square residual (WRMR).³⁸⁻⁴⁰ Examination of RMSEA values below 0.10, CFI values above 0.95, and WRMR values below 1.0 suggest approximate model fit. Modification indices, standardized factor loadings, and residuals were used to assess localized areas of ill fit. Missing data were handled by pairwise deletion, which treats missingness as a function of the observed covariates but not of the observed outcomes.^{41,42}

We used the MPlus Editor 7 (Los Angeles, CA: Muthén & Muthén) for all modeling and SAS 9.4 (SAS Institute Inc., Cary, NC, USA) for all data cleaning, recodes, and descriptive analysis. To reduce the risk of a Type 1 error, HINTS-supplied survey weights using jackknife variance estimation techniques were incorporated into analyses to account for the complex HINTS sampling design and to calculate nationally representative estimates.⁴⁴ We did this by using the TYPE = COMPLEX option in the ANALYSIS command of Mplus and specified the weight and replicate weight variables in the data.

Results

Table 1 displays the sociodemographic, clinical, and cancer-related characteristics of the sample and is representative of the US population of breast and colorectal cancer survivors. The majority of the sample was non-Hispanic (NH) white, breast cancer survivors, over the age of 50, with a high school degree or higher. Nearly the entire sample reported having health insurance, and more than half had an income less than \$50,000.

Table 2 characterizes the prevalence of survivors receiving an SCP and proximal and distal outcomes of SCP delivery identified in our conceptual framework. Almost a third of respondents indicated that they did not receive an SCP from their provider but, on average, report high levels of PCC and feel confident in their ability to manage their health. Nearly 72.3% of breast and colorectal cancer survivors are not meeting the recommended NCCN guidelines for physical activity. However, 66.9% are meeting guidelines for fruit and vegetable intake, and 62.0% report never smoking. Despite the sample reporting an average of nearly two chronic conditions in addition to cancer and BMIs within the overweight range, breast and colorectal survivors reported their perceived overall health to be good at 3.1.

Confirmatory Factor Analysis

Our CFA assessed the adequacy of the hypothesized measurement model consisting of two latent variables and six manifest variables (Figure 2). As illustrated in Table 3, the proposed measurement model fit the data adequately well. Physical activity and fruit/vegetable intake loaded significantly onto health behaviors. Although smoking did not have a significant factor loading, the item was retained. The standardized factor loadings for the items loading onto physical health latent variable were statistically significant and above 0.45, suggesting that all indicators were moderately correlated with the latent factor with which they were hypothesized to be related. Next, we examined the intercorrelations between the latent constructs and found there to be a significant correlation between physical health and health behaviors. The strength of the correlation between the two latent variables suggests that the constructs hypothesized to represent distinct phenomena are closely related and may not be distinct. As a result, health behaviors and physical health served as the final outcomes of the hypothesized structural model.

Final Structural Model

We tested the full hypothesized structural model and found that the model did not fit the data well, and the total and direct effects of SCPs to proximal and distal outcomes was not significant. As a result, receipt of an SCP was removed from the final structural model, and PCC served as the primary predictor. The results of the final structural model with the standardized regression coefficients are presented in Figure 3. Table 4 provides the overall fit statistics and the standardized direct, indirect, and total effects of the final model.

The overall fit statistics indicate that the model fit the data adequately with a chi-square of 28.379 ($df = 16$, $p\text{-value} = 0.03$), RMSEA = 0.07, CFI = .88, and WRMR = 0.73. PCC had a significant direct effect on health self-efficacy and physical health but not on health behaviors. Health self-efficacy had a significant direct effect on physical health and health behaviors, but we did not find any significant indirect effects via health self-efficacy. Since the indirect effect of PCC on physical health via health self-efficacy was approaching significance and the significant direct effect of PCC on physical health was borderline, we tested the structural model in a larger sample of breast and colorectal cancer without restricting for completion of treatment (Appendix D). The point estimates in both models were similar, but the $p\text{-values}$ for the direct effect of PCC to physical health was no longer significant while the indirect effect via health self-efficacy was significant. This finding suggests that the effect of PCC on physical health may be completely mediated by health self-efficacy.

Discussion

To our knowledge, these analyses are the first attempt to simultaneously test hypothesized pathways linking the receipt of an SCP to proximal and distal outcomes at a

survivor-level using a nationally representative sample of colorectal and breast cancer survivors. We identified latent measures for health behaviors and physical health and tested an a priori conceptual model that adapted Parry's framework for Survivorship Care Planning Research by incorporating Lafata's Patient-Clinician Communication Model to clearly define hypothesized pathways linking SCPs to proximal and distal survivor-level outcomes. SEM allowed us to test multiple relationships simultaneously within a conceptual model where mediating variables are suspected of having complex intercorrelations. However, future prospective studies are needed to account for the complexities of these relationships and further delineate potential causal pathways.

Overall, we found that the receipt of an SCP did not have a significant total or direct effect on any outcomes identified in our conceptual framework. This finding is consistent with published research suggesting that receiving an SCP alone is not likely to influence survivor-level outcomes.^{12,13} Yet, researchers continue to call for more research to identify a core set of proximal outcomes on SCPs that includes measures of patient knowledge, patient-provider communication quality, and understanding of provider roles.¹³ Null findings may be due to the limitations of the HINTS survey item serving as a proxy of SCP receipt and the inability to measure immediate outcomes of SCP receipt such as knowledge in survivorship care that may be antecedent to and inform subsequent communication exchanges. The timing between the receipt of an SCP with completing cancer treatment may also contribute to null findings. It is possible that the survivors do not remember if they received a care plan or did not receive a care plan because respondents completed treatment prior to the CoC mandate for SCP delivery. Besides, the impact of SCPs may be lost as part of the information

exchange captured by the PCC items. Therefore, future studies should assess proximal outcomes of SCP delivery in survivors who recently completed active treatment.

Results from this study emphasize the role of PCC in survivorship care and build upon the evidence regarding the mechanisms through which PCC affects survivor-level outcomes. Aligned with the framework proposed by Lafata et al., we found that PCC had a significant direct effect on health self-efficacy and physical health.^{25,45} We also found that PCC may contribute indirectly to physical health via health self-efficacy.²⁵ High-quality PCC will remain essential as medical payment programs consider care team communication as an indicator of patient-centered care.⁴⁵⁻⁴⁷ Engaging in the six core functions of PCC is particularly important to the quality of the care experiences of survivors, who face challenges relating to the management of late and long-term effects.^{25,30,45,48} Given the importance of PCC in improving cancer care quality and outcomes, future interventions of survivorship care planning should focus on improving communication between the survivors and care teams.

Survivors are becoming increasingly responsible for self-managing their health by reducing the impact of consequences due to the cancer and its treatment on functioning in daily life and for adopting behaviors that can facilitate recovery and to minimize late effect risks.^{49,50} Health self-efficacy is central to survivors managing the consequences of cancer and its treatment, understanding how and when to seek support, recognizing and reporting signs and symptoms, and adhering to lifestyle and clinical recommendations that promote survival.⁵¹⁻⁵³ Consistent with published research, we found that health self-efficacy had a significant direct effect on lifestyle behaviors and physical health.^{51,54,55} Although interventions promoting self-management exist aimed at increasing survivors' self-efficacy,

few are facilitated by care teams.⁵⁶ Future research should explore ways to integrate self-management interventions into the survivorship care planning process to promote improvements in long-term outcomes.

Strengths and Limitations

This was a cross-sectional study limiting our ability to make causal inferences from our findings or account for the timing of the exposure, mediators, and outcome variables. We assumed all variables were stable moving in a single direction, although the relationship of some variables may be bidirectional. The HINTS survey is also self-report, potentially resulting in over-reporting and recall bias. Our sample size also limited our ability to test meaningful differences in the structural model by subgroups. Future studies should measure outcomes identified in this study and assess differences in the structural model by cancer site and within underrepresented populations who bear a disproportionate burden of cancer and challenges following active treatment.

The variables and responses coded in the HINTS dataset may not capture the complexity of outcomes or the relationship among variables. Our measure of health self-efficacy consisted of a single item that was broadly applicable to one's overall health. Self-efficacy is a general trait that is likely to change based on the task to be self-managed and is subject to change over time. Moreover, the PCC items utilized in this study may not comprehensively capture the complexity of the six core functions of PCC in cancer survivorship. The PCC items also do not specify whether survivors are reporting communication and care experience with oncologists or other types of healthcare providers. In addition, this study is limited by a lack of data on provider characteristics such as length of relationship with a provider, important for establishing trust and rapport.

Despite these limitations, our findings are useful for exploratory analyses to generate hypotheses and explore the use of SEM in epidemiological studies. The HINTS dataset is also one of the few publically available datasets with comprehensive measures associated with survivorship care. Finally, the items within the HINTs dataset are also applicable to one's health and healthcare experience more broadly.

Conclusion

A better understanding of the complex relationships between SCPs and survivor-level outcomes is critical as we continue to improve survivorship care and has implications for organizations allocating time and money to the development and receipt of SCPs. To this end, it may be time to move beyond studies that look at SCPs in isolation and instead conduct research in which SCPs are embedded in evaluating the effectiveness of different models of survivorship care.^{13,23} This study examined a conceptual framework among a nationally representative sample of cancer survivors and identified PCC and health self-efficacy as potential target areas for future interventions that may influence long-term health outcomes. Finally, our findings help to inform the selection of more appropriate outcomes for measuring the impact of SCP delivery. More proximal outcomes of SCP delivery may include understanding of survivorship issues or a greater amount of information received.⁵⁷ SCP may also impact specific aspects of PCC such as the communication exchange but is unlikely to facilitate changes in health self-efficacy, adherences to health behaviors, or overall physical health. Future studies should continue to explore the underlying mechanisms linking the process of survivorship care planning to survivor-level outcomes, in samples that reflect the diversity in survivor populations and clinical settings.

Tables and Figures for Paper 1

Tables for Paper 1

Table 1. Respondent Sociodemographic, Clinical, and Cancer-related Characteristics	
	N (Weighted % ^a)
Cancer Type	
Breast	158 (73.8)
Colorectal	54 (26.2)
Time Since Completing Treatment	
< 1 year	19 (10.0)
1-5 years	57 (23.1)
5-10 years	59 (26.2)
> 10 years	77 (40.7)
Gender	
Male	24 (8.7)
Female	184 (91.3)
Age Group	
18-49	8 (3.1)
50-64	70 (37.9)
65-74	69 (27.2)
75+	60 (31.8)
Education	
Less than High School	25 (14.8)
High School Graduate	57 (27.6)
Some College	61 (28.7)
College Graduate or More	66 (28.8)
Race	
NH White	132 (82.1)
NH Black	32 (2.8)
Hispanic	15 (1.1)
NH Other	11 (1.4)
Income	
Less than \$20,000	54 (25.1)
\$20,000 to < \$35,000	37 (17.4)
\$35,000 to < \$50,000	24 (8.7)
\$50,000 to < \$75,000	28 (19.3)
\$75,000 or More	43 (29.5)
Health Insurance	
Yes	199 (95.0)
No	10 (5.0)

^a Sample and replicate weights were applied to account for the complex survey design and to ensure estimates are representative of the US population. Some values may not equal 100.

Table 2. Description of HINTS Variables

	Mean (SE) or Frequency (Weighted % ^a)
Receipt of SCP	
Yes	86 (38.1)
No	123 (61.9)
Patient-Centered Communication ^b	20.7 (0.3)
Health Self-Efficacy ^c	3.7 (0.1)
Lifestyle Behaviors	
Aerobic physical activity	
0 min/week	84 (39.6)
0-149 min/week	76 (32.7)
>150 mins/week	51 (27.7)
Fruit/Vegetable Intake	
< 3-5 servings/day	84 (33.1)
> 3-5 servings/day	128 (66.9)
Tobacco Use	
Never	128 (62.0)
Former or Current	82 (38.0)
Physical Health (PH)	
Body Mass Index (BMI)	28.7 (0.9)
Number of Chronic Conditions	1.7 (0.1)
Self-reported Physical Health ^c	3.1 (0.1)

Abbreviations: SD, Standard Deviation

^a Sample and replicate weights were applied to account for the complex survey design and to ensure estimates are representative of the US population.

^b Overall score of the sum of six items on a 4-point likert scale with higher scores indicate higher values on construct (range of scores 9-24)

^c 5-point likert scale with higher scores indicating higher values on construct (range of scores 1-5)

Table 1.3 Standardized Factor Loadings for Latent Structure for Lifestyle Behaviors and Physical Health	
Parameters	17
Fit Indices	
Chi-Square p-value	0.23
RMSEA	.04
CFI	0.96
WRMR	0.49
Standardized Item Loadings	<i>b</i> (SE)
Health Behaviors (HB)	
PA	0.96 (0.18)***
Smoke	0.12 (0.16)
FV	0.45 (0.13)***
Physical Health (PH)	
Self-reported health	0.59 (0.10)***
BMI	-0.47 (0.12)***
# of Chronic Conditions	-0.65 (0.08)***
PH with HB	0.63 (0.15)***
* P-value < 0.05	
*** p-value < 0.01	

Table 1.4 Standardized Total, Direct, and Indirect Effects for Paper 1		
	<i>b</i> (SE)	<i>p</i> -value
Patient-centered communication to Physical Health		
Total effect	0.34 (0.11)	<0.01
Indirect effect	0.11 (0.06)	0.06
Direct effect	0.23 (0.12)	0.05
Patient-centered communication to Health Behaviors		
Total effect	0.27 (0.12)	0.02
Indirect effect	0.09 (0.07)	0.21
Direct effect	0.18 (0.13)	0.14

Figures for Paper 1

Figure 1. Hypothesized pathways linking SCPs to Proximal and Distal Outcomes

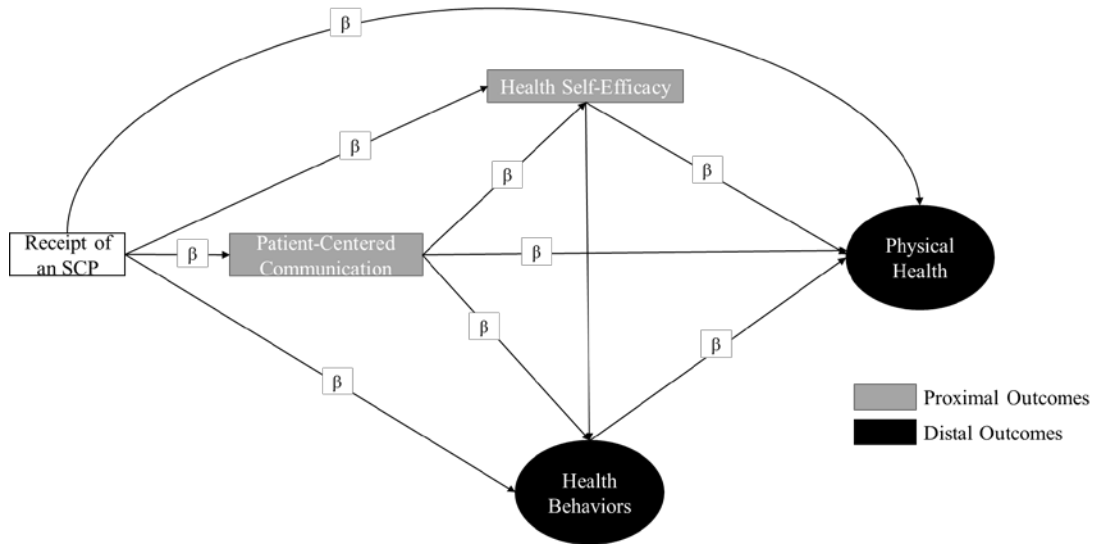


Figure 2. Hypothesized Measurement Model for Health Behaviors and Physical Health

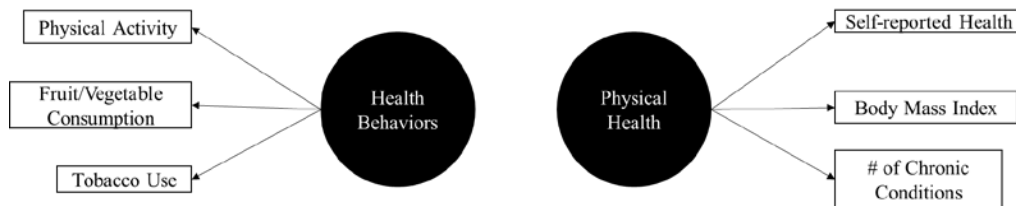
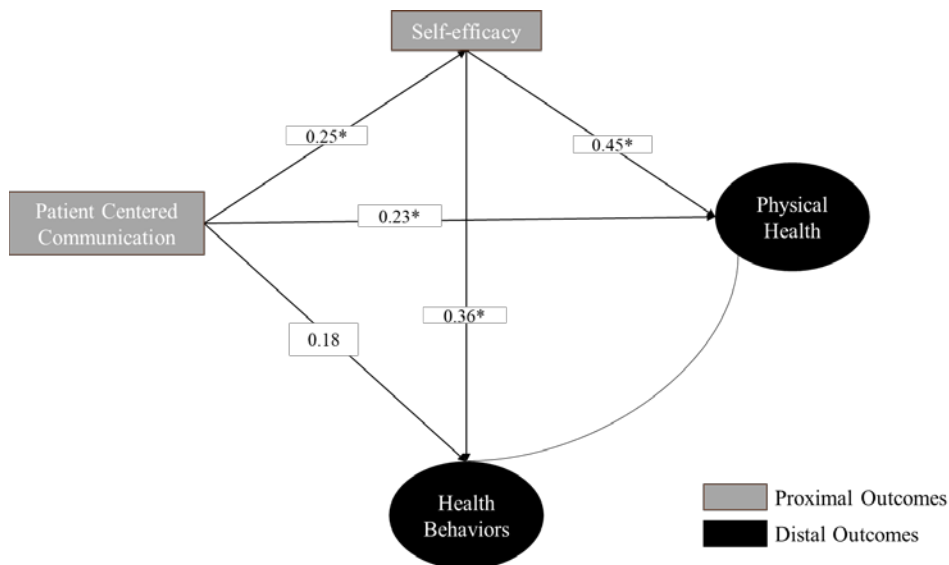


Figure 3. Standardized results for the final structural model



Notes: *significant at $p < 0.05$

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JOURNAL ARTICLE 2

Working Title: Experiences and Outcomes of Survivorship Care Planning among Safety-Net Colorectal and Breast Cancer Survivors: A Qualitative Study.

Name of Journal Proposed for Article Submission: Journal of Clinical Oncology

Introduction

Breast and colorectal cancer survivors represent two of the most prevalent cancers in females and comprise nearly a third of the total cancer survivor population.¹ Cancer survivors, defined as patients who have completed active treatment, are at increased risk for poor health outcomes post-treatment.²⁻⁴ Under- and un-insured patients, such as those served by safety-net settings, bear a disproportionate burden of cancer and experience disparities in survivorship outcomes due to suboptimal patient-provider communication, inadequate supportive resources, and low access to and awareness of health information resources.^{5,6}

The Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*, has sought to establish the essential elements of any model of survivorship care planning: surveillance for recurrence, screening for secondary cancers, assessment and intervention for long-term/late-effects, counseling on healthy lifestyle behaviors, and communication/coordination with primary care.⁷ Several models of survivorship care exist directed toward a common goal of improving the quality of survivorship care following the completion of active treatment.^{6,8} Routine delivery of a survivorship care plan (SCP) remains the dominant approach of most models, where delivery is intended to facilitate communication between patients and providers and amongst providers.^{7,8,9} In the decades following the release of the IOM report, several high-profile organizations have mandated the delivery of SCPs concluding that SCPs have strong face

validity as a tool for navigating post-treatment care.^{7,9} In fact, qualitative studies with under- and underserved cancer survivors found SCPs to be acceptable and helpful following the completion of active treatment.^{10,11}

A number of previous studies have examined the effectiveness of SCPs on health and health care outcomes with mixed results.¹² Observational studies have attributed a positive effect of SCPs on survivor-level outcomes including satisfaction with care¹³, patient-provider communication^{14,15}, confidence in one's ability to manage care (self-efficacy)¹⁶, and to changes in lifestyle behaviors.¹⁷ However, findings from randomized controlled trials show no effect on patient-reported health states and perceptions of care.^{18,19} Among the few significant findings in RCTs, results suggest that SCPs may beneficially affect health worry²⁰, information received²¹, and satisfaction with care.²²

Inconsistencies in SCP effectiveness may be partly due to variation in outcomes measured across studies and a limited understanding of the types of outcomes that SCPs are likely to influence.^{23,24} Moreover, much of the research around SCPs have focused on addressing informational needs by improving the content, use, and delivery of SCPs; few examine the survivor's own perspectives regarding the care planning experience.¹¹ To this end, more work is needed to identify and refine the survivor-level outcomes most relevant to patients, notably with more diverse populations and settings.²³⁻²⁶ Importantly, outcomes should be "patient-centered", capturing the most relevant health effects and other consequences following cancer treatment.^{23,25,27} Therefore, the objective of this paper is to elucidate the survivor's experience with survivorship care planning and elicit perspectives about relevant outcomes among breast and colorectal cancer survivors receiving care at a large, urban integrated safety-net health system. Findings from this paper may help to inform

new models of survivorship care by elucidating possible mechanisms through which SCPs and care planning process impact outcomes and by identifying key targets for future interventions.

Methods

Study Design

We employed a qualitative research design and invited a purposeful sample of colorectal and breast cancer survivors to participate in a 30 minutes semi-structured telephone interview. We drew this sample from those currently enrolled in a larger quasi-experimental hybrid implementation-effectiveness study (NCI R01CA203856- Project CONNECT) of evidence-based care coordination strategies for patients with pre-existing chronic conditions and an incident cancer diagnosis. This study was approved by the University of Texas Southwestern Medical Center, Parkland Health & Hospital System Office of Research Administration, and the University of Texas Health Science Center at Houston Institutional Review Boards (IRB).

Recruitment and sample

Participants were recruited from a large, urban county integrated safety-net health system in Texas accredited by the *American College of Surgeons Commission on Cancer*, thus mandated to provide all survivors with an SCP, making them an ideal population for understanding experiences with survivorship care planning. Safety-net providers serve patients regardless of their ability to pay, whose patient mix includes substantial numbers of uninsured, Medicaid, and other vulnerable populations.²⁸ Using electronic health record data and registry data, we identified patients diagnosed with stage I, II, and III breast or colorectal cancer who completed active treatment in the last 18 months. We defined the completion of

active treatment as the completion of initial surgical treatment and/or initial adjuvant chemotherapy and radiation. Those with in situ (stage 0) and metastatic disease (stage IV) were excluded because they are unlikely to receive a SCP. Those with impaired hearing or speech and/or the inability to comprehend or speak English, were also excluded from participation. We identified 26 eligible participants who completed a survey about their cancer care experience and indicated that they were interested in completing a follow-up interview with the research staff.

Procedure

A non-proportional quota sample was chosen from eligible participants who expressed an interest in taking part in an interview with the research team. Initially, research staff aimed to recruit a diverse sample of survivors to examine potential differences in post-treatment experiences and outcomes by cancer site (50% Breast, 50% Colorectal). Participants were selected to populate the cancer site subgroup with the aim of recruiting a maximum of 10 participants who completed treatment in the last 18 months. Between May and July of 2019, we reached out to 22 eligible participants for an interview and completed nine interviews (eight women and one male). Due to challenges recruiting males and a limited number of colorectal patients meeting eligibility criteria, the team made the decision to limit the sample to women only to increase the potential to reach saturation. The sampling strategy was modified to represent the demographic and cancer related distribution of breast and colorectal cancer survivors at the county system (70% racial/ethnic minorities, two-thirds breast cancer). All interviews acquired informed consent and were performed using a semi-structured interview guide by a trained member of the research staff. Interviews were audio-recorded and transcribed verbatim. Participants were compensated \$20 for their time.

The interview guide was informed by our conceptual framework that integrated Parry et al. model of Survivorship Care Planning Research with Lafata et al. model of Patient-Clinician Communication and further included pathways identified in observational studies linking SCPs to proximal and distal survivor-level outcomes (Figure 1). Parry et al. proposed a clinical framework based off the landmark IOM report in which SCPs facilitate patient-provider communication, in turn, resulting in improvements in survivor-level outcomes, such as management of late effects, and long term physiological and psychosocial outcomes.²⁵ Given that recommendations for SCPs explicitly state that communication between patients and providers, or “patient-centered communication” (PCC), is central to delivering high-quality survivorship care,⁹ we included Lafata et al. conceptual framework that suggests that the communication exchange between the patient and provider may result in improved health outcomes, primarily indirectly through affective-cognitive outcomes, such as health self-efficacy, and behavioral outcomes, such as physical activity and diet.^{29,30} Finally, our conceptual framework also includes two direct pathways supported by observational studies linking SCPs to increased confidence in one’s ability to manage care and changes in health behaviors.^{16,17}

Our semi-structure interview guide was informed by this integrated conceptual framework and focused on the women’s experience with survivorship care planning and their experience following the care planning visit. We asked women to reflect on their last treatment visit with their oncology care team to understand their experiences with survivorship care planning. Specifically, we asked the women to recall the information they received and discussed with their oncology care team during their last treatment visit. To elucidate potential outcomes of survivorship care more broadly, we asked participants to

describe their post-treatment experience. We probed participants to discuss how they knew they were doing well post-treatment and to identify the most important thing they could do to stay healthy after cancer treatment. See Appendix B for the final interview guide.

Analysis

All data was professionally transcribed, de-identified, and analyzed in NVivo (QSR, International, AUS). Two members of the research team performed thematic content analysis using a deductive-inductive approach.³¹ Each transcript was first reviewed in its entirety to allow themes and subthemes to emerge. Then, drawing on constructs from our conceptual model, we developed a deductive code structure that was applied to three transcripts during an initial open coding session. As new ideas emerged, the research team considered inductive themes and domains, allowing the codebook to evolve.^{32,33} The revised codebook was then applied to the five remaining transcripts. The team coded the transcripts independently before coming together to compare codes. All discrepancies in codes were resolved through consensus and analysis continued until no new ideas emerge from subsequent interviews and resulting themes were deemed saturated.³⁴

Results

We analyzed a total of eight interviews with female breast and colorectal cancer survivors who completed treatment in the last 18 months. Table 1 outlines their demographic, clinical, and cancer-related characteristics. The women were between the ages 49-70 (mean 57 years), approximately two-thirds were non-Hispanic (NH) black. Only one woman had Medicare insurance, seven were on Medicaid or were uninsured (receiving some form of county medical assistance), and most had a diagnosis of hypertension and diabetes that predated their diagnosis of cancer.

Analysis of the eight transcripts identified four overarching themes, which subsumed several domains as shown in Table 2. Our themes can be divided into two main categories - themes specific to the process of survivorship care planning and themes related to survivorship following the care planning visit. We defined the survivorship care planning visit as the last treatment visit with the oncology care team when survivors should be receiving and reviewing an SCP. We also identified three inductive themes that provided insight into additional outcomes and future targets of survivorship care research. A description of themes and domains with supporting quotes can be found in Appendix E.

Experiences with Survivorship Care Planning

Patient-Provider Communication

We asked the women to reflect on their last treatment visit, at which survivorship care planning should take place, with their oncology care team focusing on the last communication exchange and the information they received to characterize relevant survivor-level outcomes of survivorship care planning. All women reported that they had a positive communication experience with their oncology care team.

Giving Information – Verbal and Written

We asked the women what their oncology care team told them during the last treatment visit, and if they received any written information without explicitly asking about SCPs. The women describe how a member of their oncology care team performed a physical exam and provided updates on their physical condition related to the cancer treatment and reviewed the next steps in their cancer care. The women also reported that their oncology care team provided them with written information to take home and reviewed the information during the visit.

They [oncology providers] provided me with the information. Not just tell me, they also gave me the printout of what I needed to do and how I needed to take care of myself and what to expect (49 year old, NH black, stage III colorectal cancer survivor).

[The papers] you know, stuff like if I'm hurting or sore and it showed me how to take care of the wound that I had on my stomach, and if I have any problems, I call the nurse if I feel pain. (53 year old, NH black, stage II colorectal cancer survivor).

According to the women, the paperwork they received during their last treatment visit included information such as upcoming appointments, contact information, instructions on how to take care of oneself, and a list of possible symptoms that warrant their attention. Although the women did not explicitly state that they received an SCP, they did find the written information they received to be helpful by serving as a reminder for upcoming appointments. However, it was unclear if the written information included cancer surveillance guidelines although a few women reported knowing they needed to attend follow-up appointments to make sure the cancer did not return.

Eliciting Questions or Concerns and Ensuring Patient Understanding

We further probed the women to see if they felt comfortable asking questions and if their oncology care team ensured that they understood the next steps in their cancer care.

She [provider] actually go over it with me and then ask me if I have questions about what she just talked about and if I have a question, I'll ask her (59 year old, NH black, Stage III breast cancer survivor).

I'll talk to the oncologist and then she'll say- do you understand?- and I'll be like- Yes. And she'll say- Okay, well explain to me what I told you (54 year old, NH white, stage I breast cancer survivor).

The women described how their oncology care team would review the information and then elicit questions about the information they received. The women also reported that their

oncology care team ensured that they understood the information provided by asking them directly or by having them repeat back what was discussed. Finally, the women reported that their oncology care team sent them home with a list of individuals to contact if they have any additional questions or concerns.

Responding to Patients Needs and Care Team Responsiveness

We asked the women if their oncology care team responded to feelings of uncertainty, stress, worry, and overall needs during their last treatment visit. The women describe how their oncology care team showed interest in and sensitivity to their needs by providing ongoing support and encouragement. The women emphasized how the emotional support from their oncology care team helped to alleviate negative feelings or worries about the next steps in their care. The women also stated that it was important for their oncology care team to be available for questions or concerns outside of the last treatment visit and appreciated when they received a timely response.

I was scared and I told my doctor and they said- We at [hospital], we're always going to take good care of our patients and that's what I like to hear. If a doctor to tell me that, I'm not scared no more (53 year old, NH black, stage II colorectal cancer survivor).

...she called me back when she did it, and she actually faxed it all for me and called me and let me know that I could come and pick up the original if I needed it. So she's pretty good about following up with anything I need (59 year old, NH black, Stage III breast cancer survivor).

Challenges in Communication

Although the women generally reported positive communication experiences during the last treatment visit, a few women did report challenges communicating with oncology

and non-oncology providers outside of the care planning visit. One woman described how she did not like seeing different oncologists or “interns” at each visit and two women described their frustration with non-oncology care team members, such as primary care providers, not being informed about their cancer treatment.

Well, he just needs to be informative, my primary care physician. I mean I know he sees a lot of people, but he’s like- Oh, okay well what did they [oncology] say? Well, you should know what they said (52 year old, NH black, stage III colorectal cancer survivor).

Oncology Care Team Responsibilities

We asked the women what their oncology care team can or are currently doing to help them stay healthy post-treatment. The women stated that their oncology care team was helping them stay healthy post-treatment by scheduling appointments and ordering the necessary labs/radiology based on their needs. In addition, the women reported that their oncology care team would refer them to non-oncology care team members, local support groups, financial assistance programs, and exercise and nutrition resources as needed.

She’s got all these appointments scheduled for me, all this lab work scheduled for me ... (54 year old, NH white, stage I breast cancer survivor).

He sets up the appointments I ask for and stuff, and he gets to the bottom of the problem. If he can’t, he sets you up with somebody else that can (56 year old, NH white, stage II breast cancer survivor).

Experiences and Outcomes of Survivorship Care

Post-Treatment Experience

The women were asked to reflect on their experience since their last treatment visit to identify relevant outcomes of survivorship care overall and to understand the impact of survivorship care planning on more distal outcomes. The women’s description of their post-

treatment experiences comprised three broad domains: 1) physical and mental health symptoms, 2) returning to normal daily living patterns, and 3) unexpected experiences.

Physical and Mental Health

The women primarily described their post-treatment experience as the presence or absence of physical symptoms resulting from cancer and its treatment. The most common physical symptoms experienced included pain, swelling, and fatigue.

Well, I got a lot of other problems other than that so I still stay tired a lot... Yeah from my- and my bones hurt and stuff like that, but it's not from the cancer. It's from everything else that's wrong with me (56 year old, NH white, stage II breast cancer survivor).

The women also acknowledged the presence of symptoms related to their other chronic conditions but made efforts to distinguish between symptoms related to cancer versus symptoms due to other chronic conditions. The women did not openly discuss their mental health symptoms until probed by the interviewer. When probed, seven out of the eight participants reported that they were not currently experiencing mental health symptoms. However, two out of the seven reported poor mental health following initial diagnosis or immediately following treatment and one woman reported that she was currently experiencing poor mental health symptoms.

Mentally, uh not very good... Not very good, and I think it's mostly because of not knowing, you know, what the mastectomy would actually look like (59 year old, NH black, Stage III breast cancer survivor).

The women characterized mental health symptoms as the presence or absence of stress, worry, anxiety, and depression and stated that the presence of mental health symptoms was often a result of unexpected side effects of cancer and its treatment.

Unexpected Experiences

We asked the women if anything unexpected occurred following the end of their cancer treatment. The women reported that their oncology care team prepared them for life post-treatment by telling them what to expect. Despite being informed about the side effects of cancer and its treatment, about half of the women reported that they were not prepared for the severity and longevity of symptoms they experienced.

You hear about going through the chemo and all the side effects and I guess I didn't expect it to be as bad as it was with the side effects for the chemo, but I mean I knew about them, I just had never personally experienced them so I wasn't ready for those side effects like the hair loss, the nausea, the vomiting. I wasn't expecting it to be as bad as it actually was (54 year old, NH white, stage I breast cancer survivor).

Return to Pre-Cancer Function

The women were asked how they knew they were doing well following cancer treatment. The women reported that an indicator of doing well after treatment was the return to pre-cancer function. The women describe pre-cancer function as the reduction of symptoms and being able to do the things they used to before their cancer treatment such as daily living activities and returning to work.

Well, so far I'm doing fine. I don't have no symptoms or nothing. No bad symptoms or nothing...I went back to work and everything (49 year old, NH black, stage III colorectal cancer survivor).

Adherence Behaviors

We asked the women what they felt was the most important thing they could do to stay healthy following cancer treatment, and all described the need to engage in adherence behaviors including activities that fall under cancer surveillance and healthy lifestyle behaviors.

Engaging in Cancer Surveillance and Healthy Lifestyle Behaviors

The women acknowledge the importance of engaging in cancer surveillance behaviors, such as attending follow-up appointments and receiving appropriate labs/radiology to ensure that the cancer did not return or spread. Many describe engaging in cancer surveillance activities as doing “*exactly what the doctors and them tell me to do*”.

Well, I need to continue with all of the follow-ups. I need to have my CT scans done on a regular basis to make sure that none of it has gotten any larger and that it's not in other places, things like that (54 year old, NH white, stage I breast cancer survivor).

I gotta take my pills for five years. I can't run out of them. I always get them, and I take one every- one a day (70 year old, NH black, breast cancer survivor).

The women did not specify who was responsible for which aspects of these cancer surveillance activities. Interestingly, the women did not mention the management of other chronic conditions as part of cancer surveillance.

The women also discussed the importance of engaging in healthy lifestyles behaviors, such as diet, exercise, and smoking cessation to their overall health following cancer treatment. Specifically, the women stated that they were currently engaging in at least one behavior and emphasized the importance of eating right and exercising to reach or maintain a healthy weight.

So yeah just walking, just light general exercise...not overeating and I've started to lose some weight now. Let's see- yeah, I'm just making healthy choices food wise and exercise wise or movement wise (65 year old, NH white, stage I breast cancer survivor).

The women also acknowledged that their oncology care team and other non-oncology providers discussed the importance of maintaining a healthy weight and engaging in healthy

lifestyle behaviors to their health. However, the women did not specify when the care team made these recommendations and if they reiterated these recommendations during the survivorship care planning visit. A few women did report that despite being told to exercise, diet, or quit smoking, this did not always translate to the desired behavior.

... because I mean they've always told me from the time I had my daughter that I needed to lose weight, and I just never did it so and I mean I've known that I needed to cut down on the sugar and the sweets and the cokes and things like that and there again, I didn't do it. It was my choice not to do it so I can't say that there's any experience that I've had that I wasn't really prepared for (54 year old, NH white, stage I breast cancer survivor).

Barriers to Engaging in Adherence Behaviors

We probed the women to discuss anything that made it difficult for them to engage in healthy lifestyle and cancer surveillance behaviors. The women identified a number of barriers including a lack of or changes in health insurance, declines in physical health due to other chronic conditions, lack of social support, and transportation.

I'm not able to afford health insurance so that would be my only thing about me being able to follow up with my health, you know, because of the financial part of it but, you know, I have to worry about that when it happens. (59 year old, NH black, Stage III breast cancer survivor).

Potential Patient-Outcomes of Survivorship Care and Care Planning

We asked the women if they felt good about their ability to manage their health following cancer treatment, or their cancer management self-efficacy. The women generally felt good about their ability to manage their cancer health because they were more aware of the signs and symptoms of cancer and that their oncology care team gave them the “tools” they needed to take care of their health after cancer. In addition, the women described the role of social support and motivation in managing their health after cancer treatment.

Specifically, the women discussed how going through cancer treatment gave them the motivation they needed to stay healthy and engage in healthier behaviors so that they could be around for family and friends. The women also described the importance of having social support from family, friends, and oncology care team members to assist with daily living activities, encouraging healthy lifestyle behaviors, and providing ongoing information and support.

So I got a motivation. Motivated to stay healthy enough to where I'll be around for a while (56 year old, NH white, stage II breast cancer survivor).

They both work, we're roommates so there's- like last night. I couldn't cook. I was nauseous, you know, hey- y'all are going to have to cook. Yeah, so that's just how it works around here when I get sick, I start slowing down, and they're like- I think you need to go get checked out (56 year old, NH white, stage II breast cancer survivor).

Characterization of Survivor-Level Outcomes

Based on the analysis of interview data, we characterized survivor-level outcomes of survivorship care into two broad categories - outcomes related to the process of the survivorship care planning and outcomes following the survivorship care planning visit that require complex behavior change. The outcomes listed in Table 3 are not exhaustive but lay the foundation for refining the selection of the most appropriate and salient outcomes for measuring the effectiveness of survivorship care models and interventions.

Discussion

This paper sought to elucidate the experiences of survivorship care planning among female, safety-net breast and colorectal breast cancer survivors. Cancer survivors often feel unprepared for life after treatment due to a lack of information about the long-term side

effects of treatment, follow-up care and surveillance, lifestyle recommendations to stay healthy, or details related to emotional and social support.³⁵⁻³⁹ Previous qualitative studies have primarily focused on the use, content, and delivery of SCPs in isolation and fail to consider key elements of the planning process, such as the communication exchange between the survivor and oncology care team.^{11,40,41} We were explicitly interested in elucidating survivors' experience with the process of survivorship care planning rather than the content and delivery of an SCP. Overall, we found that our female, safety-net breast and colorectal cancer survivors reported positive experiences with the survivorship care planning process and felt that their oncology care team prepared them for life post-treatment.

Our findings underscore the essential role of patient-centered communication (PCC) with oncology care teams, not just the presence or absence of SCPs, in delivering high-quality survivorship care planning.^{7,42} Several recent studies have shown that PCC following active treatment is suboptimal, with gaps in communication most problematic among cancer survivors with multiple chronic conditions.⁴³⁻⁴⁵ However, we found that female, safety-net cancer survivors with multiple chronic conditions reported positive communication experiences with their oncology care team that aligned with the six core functions of PCC: 1) Fostering healing relationships; 2) Exchanging information; 3) Responding to emotions; 4) Managing uncertainty; 5) Making decisions; and 6) Enabling patient self-management.^{40-42,46} Specifically, we found that the oncology care team gave and reviewed information in a way that was easy to understand, created an open environment to ask questions, and ensured patient understanding using methods shown to promote knowledge and self-efficacy.^{47,48} The oncology care team was also responsive to the survivors' needs, emotions, and feelings of uncertainty during and after the survivorship care planning visit. Our findings suggest that

PCC may be critical to increasing knowledge in survivorship care, satisfaction with the information and care received, and increasing confidence in the women's ability to identify signs and symptoms of cancer recurrence.^{30,43,47-52}

This study highlights gaps in the current conceptualization of the survivorship care planning process that have important implications for long-term health. Previous research has primarily conceptualized survivorship care planning from a health services delivery lens; focusing on system-level approaches to improve the delivery and receipt of SCPs to survivors and non-oncology care team providers, such as primary care. By focusing on the survivors' perceived experience, the focus around survivorship care planning shifts away from the delivery of a single document and emphasizes the role of oncology care teams in engaging in high-quality PCC with survivors, coordinating cancer surveillance care activities, providing practical assistance and support to overcome barriers in care, and communicating with and coordinating care with non-oncology providers such as, primary care. These findings emphasize the need to look beyond the delivery of SCPs in isolation and focus on the processes of care through which survivorship care planning takes place.²⁵

Findings from this study suggest that the survivorship care planning process alone is unlikely to impact survivor-level outcomes that require complex behavior change. Guidelines for cancer survivors recommend that survivors engage in multiple adherence behaviors following the completion of active treatment.^{53,54} Similar to published studies, we found that the survivorship care planning process served as "teachable moment" for oncology care teams to discuss the importance of engaging in adherence behaviors with survivors.^{55,56} Previous research supports that receiving a recommendation from a provider may be a powerful predictor of behavior change.⁵⁷ However, we found that having knowledge and an

oncology care team recommendation did not always translate to the desired behavior due to a variety of factors, such as symptom burden (e.g., fatigue, pain), physical limitations as a result of their other chronic conditions, and sociodemographic barriers (e.g., insurance status, transportation). These findings support existing evidence suggesting that it may be more appropriate to assess proximal outcomes of the survivorship care planning process.²⁴ In addition, oncology care teams should also assess barriers to adherence behaviors and refer survivors to interventions with a patient-level component that targets multiple adherence behaviors.

As the focus of cancer care and control efforts shifts towards more personalized and long-term approaches, empowering cancer survivors to assume a more active role in their own health care is becoming an increasingly essential component of cancer survivorship.^{58,59} Our findings suggest effective PCC during the care planning process may promote self-efficacy in managing long-term survivorship issues.⁴⁶ Consistent with previous studies and health behavior theory, results from this study also highlight the role of perceived social support and intrinsic/extrinsic motivation on behavior change.^{60,61} We found that the women felt good about their ability to stay healthy after cancer treatment because they felt motivated by their cancer diagnosis and emphasized the role of perceived social support in engaging in healthy behaviors. Future studies should continue to explore the influence of these health behavior determinants to understand underlying mechanisms driving change and continue to explore the influence of these determinants throughout the survivorship continuum. Similarly, investigators may wish to explore study designs that prospectively collect data directly before and after end of treatment visits, even recording provider-patient dialogue during these visits

to systematically document information exchange and other proximal outcomes, for example, catching survivors on exit.

A unique feature of our study is that – drawing from a parent study in a county integrated health system – all our cancer survivors had at least one other common chronic condition in addition to cancer, and many acknowledge the impact of their other chronic conditions on the burden of symptoms experienced following cancer treatment.⁶² Persistent symptom burden following treatment has shown to reduce quality of life, adherence to follow-up care, and impacts the ability for survivors to return to daily living patterns.⁶³ Moreover, survivors may be reluctant to discuss challenges following treatment that can contribute to psychological distress.⁶⁴ These findings support the routine collection of patient-reported outcomes that consider the impact of chronic conditions among other sociodemographic and cancer-related characteristics in research and clinical care to identify and control for problems that may be overlooked within the care planning process.^{62,65,66} The presence of multiple chronic conditions also creates the added burden of managing multiple care teams even within a county integrated system, resulting in gaps in communication between care teams and suboptimal care coordination.^{7,67-69} In other settings outside of Parkland, where care is more fragmented, oncology and primary care for survivors may be even more siloed. Our findings allude to communication and care coordination between care teams members as an issue that will impact all cancer survivors.⁷⁰ SCPs may help to facilitate better communication and care coordination between care teams but it is unclear from our results if non-oncology care teams, such as primary care, are receiving a care plan and are accountable for acting on it.⁷ To this end, it may be appropriate to assess perceived care coordination and satisfaction with

care to account for communication and care coordination between oncology and non-oncology care teams.

Although our findings represent a significant contribution to the literature, our study has a number of limitations. The analysis of qualitative data does not allow for causal inference and cannot be generalized to other settings caring for safety-net breast and colorectal survivors. The nature of our interview sample limited our ability to look at other factors such as race/ethnicity, socioeconomic, clinical, and cancer-related characteristics in a meaningful way. Our findings may also be limited by recall bias given that survivors with multiple chronic conditions may have trouble recalling who they saw, when, and what was discussed. Social desirability may be another limitation since safety-net survivors may feel the need to speak positively about the oncology care team to continue receiving quality care, although candid reports in our study suggest this was unlikely, nonetheless social desirability was not measured.

Despite these limitations, our study has notable strengths. Using a qualitative study design allowed for an in-depth understanding of subtleties and complexities around the survivorship care planning process and provided perspectives of safety-net populations that have been underrepresented in research to date. In addition, our sample was representative of the safety-net breast and colorectal cancer survivor population at our large urban setting and is one of the few studies to elucidated perspectives among survivors across multiple cancer sites. Finally, our findings may help to inform quality improvement targets for our research setting and serve to generate hypotheses that may be tested in future target interventions and studies.

Conclusion

To our knowledge, this is the first qualitative study focusing on the experiences with the process of survivorship care planning among safety-net breast and colorectal cancer survivors. We draw an important distinction between outcomes specific to the survivorship care planning process versus outcomes of survivorship care that may require patient-level interventions. Understanding the first-hand experiences of these survivors provided meaningful insight into the complexities of measuring the effectiveness of survivorship care models and emphasizes the need for ongoing assessment of outcomes that consider implications of cancer amidst other chronic conditions, as well as the need to assess individual-level determinants of behavior change. Finally, future studies should continue to identify and refine the most relevant survivor-level outcomes of survivorship care planning across diverse clinical settings.²³⁻²⁵

Tables and Figures for Paper 2

Tables for Paper 2

Table 1. Participants Sociodemographic, Clinical, and Cancer Characteristics	
Age (mean)	57
Race/Ethnicity	
NH White	3
NH Black	5
Insurance Status	
Medicare	1
Medicaid	3
Uninsured/Financial Assistance	4
Chronic Conditions	
Chronic Obstructive Pulmonary Disease	2
Hypertension	7
Diabetes Mellitus	6
Heart Disease	2
Chronic Kidney Disease	1
# of Chronic Condition in addition to cancer	
1-2	6
>2	2
Cancer Site	
Breast	5
Colorectal	3
Stage	
I*	3
II	2
III*	3
Months since end of initial treatment	
6-12	7
>12	1
Provider seen at last treatment visit	
Oncologist	1
Surgeon	2
Mid-Level/Nurse	3
Oncologist/Nurse	2
*Indicates that stage data was not available in the cancer registry or electronic record for participants, thus based on self-report.	

Table 2. Summary of Themes and Domains	
Themes	Domains
Survivorship Care Planning	
Patient-Provider Communication	Written and Verbal Information Exchange
	Ensuring patient understanding
	Eliciting Questions and Concerns
	Making Decisions
	Responsiveness
	Responding to Patient Needs
Oncology Care Team Responsibilities	Gaps in communication
	Setting up appointments
	Scheduling/Ordering labs/radiology
	Referring to non-oncology providers and resources
Post-Survivorship Care Planning	
Post-treatment experience	Physical Health
	Mental Health
	Unexpected Experiences
	Return to pre-cancer function
Adherence Behaviors	Cancer surveillance behaviors
	Healthy lifestyle behaviors
	Barriers to adherence behaviors
Self-efficacy	Barriers to managing health

Table 3. Relevant Survivor-Level Outcomes	
Outcomes of the survivorship care planning process	Outcomes of Survivorship
Patient-Centered Communication	Engagement in Adherence Behaviors <ul style="list-style-type: none"> Adhering to guidelines for cancer surveillance and healthy living after cancer
Knowledge of survivorship care	Perceived self-efficacy ^a
Satisfaction with information received/overall care	Motivation to engage in adherence behaviors
Perceived care coordination	Perceived social support (informational/emotional)
Perceived self-efficacy ^a	Patient-reported outcome measures
Perceived social support (informational/emotional)	

Figure for Paper 2

Figure 1. Conceptual Framework depicting hypothesized pathways linking SCPs to survivor-level outcomes.



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JOURNAL ARTICLE 3

Working Title: Leveraging an Adapted Mixed-Methods Approach to Improve Survivorship Care Planning Processes and Outcomes

Name of Journal Proposed for Article Submission: Journal of Clinical Oncology

Introduction

The continual growth in the number of survivors who are living longer after cancer coupled with the complexities of delivering comprehensive care during the survivorship phase has generated increased attention from leading health organizations to optimize survivorship care.¹⁻³ The Institute of Medicine (IOM) identified four essential components of survivorship care: 1) prevention of new and recurrent cancers; 2) surveillance for the spread, recurrence, or development of secondary cancers; 3) management of the late and long-term side effects of treatment; and 4) coordination between care teams.⁴ The use of survivorship care plans (SCPs), as well as adherence to guidelines for survivorship, have become central to the provision of quality oncology care.^{5,6}

The SCP was promoted as a means of delivering patient-centered care by facilitating communication between the oncology team and the survivors as well as communication and care coordination between the oncology care team and primary care.⁴ In addition, SCPs include information around preventive practices and recommendations for healthy living after cancer treatment. Decades following the release of the IOM report, several high-profile organizations, including the American College of Surgeons,⁷ have mandated the use of SCPs, making them the dominant approach to models of survivorship care. Yet, evidence regarding the effectiveness of SCPs on survivor-level outcomes remains mixed, and studies have shown that only 39% of cancer survivors report that a provider ever discussed lifestyle

recommendations and 32% and 12% of oncologists and primary care providers respectively report always discussing lifestyle recommendations for survivorship care with patients.⁸⁻¹⁰

Inconsistency in findings may be due to variations in outcomes measured across studies and a limited understanding of the most appropriate outcomes that SCPs are likely to influence.^{11,12} Also, few studies have focused on the context in which care plans have been delivered, which could influence the effectiveness of SCPs on health and healthcare outcomes.¹³ Researchers continue to advocate for more research to identify and refine the most relevant survivor-level outcomes to be measured in studies examining SCPs, notably with more diverse populations and clinical settings.¹¹⁻¹³ Specifically, researchers have proposed outcomes of particular focus for future research including patient-provider communication, patient engagement through enhanced self-efficacy, lifestyle behaviors, and overall health.¹⁴⁻¹⁶ However, without a guiding framework, problems are likely to persist in identifying relevant outcomes of survivorship care planning models, as well as challenges intervening without knowledge of the appropriate leverage points.

Few frameworks for survivorship care planning exist that depict the hypothesized relationships through which survivorship care planning affects survivor-level outcomes. Parry et al. proposed a clinical framework of Survivorship Care Planning in which SCPs facilitate communication and care coordination that, in turn, influence later outcomes, such as management of late effects, and long term physiological and psychosocial outcomes.¹³ However, this framework fails to consider the hypothesized indirect pathways linking survivorship care planning to improved survivor-level outcomes, notably outcomes that involve complex changes in behavior. Lafata et al. proposed a conceptual framework in which the communication exchange between the patient and the provider itself can directly

lead to improved health outcomes during and after cancer and depicts how, in most cases, communication likely affects health outcomes indirectly through affective-cognitive outcomes, such as health self-efficacy, and behavioral outcomes, such as exercise and nutrition.^{17,18} However, neither framework incorporates health behavior theory critical for understanding complex behavior change.

To date, few studies have utilized a comprehensive framework of survivorship care planning and are limited in considering the survivor's own perspectives regarding the survivorship care planning process. Much of the research around SCPs have focused on addressing informational needs by improving the content, use, and delivery of SCPs and have been limited to single cancer sites.¹⁹ The purpose of this paper is to provide a high-level synthesis of relevant survivor-level outcomes and to explore the processes behind the delivery of SCPs. We used an adapted mixed-methods approach to integrate data from multiple data sources and populations (Table 1) to refine existing frameworks on survivorship care planning and suggest future research directions related to improving our understanding survivor-level outcomes.

Methods

This study uses an adapted, mixed-methods approach. The quantitative component of the study examined the direct and indirect relationships linking SCPs to survivor-level outcomes in a nationally representative sample of breast and colorectal cancer survivors using the Health Information National Trends Survey (HINTS). The qualitative component of the study elucidates the experience with and relevant outcomes of survivorship care planning among breast and colorectal cancer survivors receiving care at a large, urban, integrated safety-net hospital. Due to differences in the sample composition between the two

data sources, we pulled an additional subset of colorectal and breast cancer survivors from the initial quantitative HINTS dataset to include only non-Hispanic (NH) white and black women with at least two chronic conditions who completed treatment in the last five years. All three samples were included in the final analysis.

Data Collection and Analysis

We analyzed the quantitative and qualitative data separately prior to integration. Integration of the data was informed by our conceptual framework for survivorship care planning research adapted Parry et al. model of Survivorship Care Planning Research with Lafata et al. model of Patient-Clinician Communication (Figure 1). Parry et al. proposed a clinical framework in which SCPs facilitate patient-provider communication, in turn, resulting in improvements in survivor-level outcomes, such as management of late effects and long term physiological and psychosocial outcomes.¹³ Given that recommendations for SCPs explicitly state that patient-centered communication is central to delivering high-quality survivorship care,²⁰ we included Lafata et al. conceptual framework that suggests that the communication exchange between the patient and provider may result in improved health outcomes, primarily indirectly through affective-cognitive outcomes, such as health self-efficacy, and behavioral outcomes, such as physical activity and diet.^{17,18} Finally, our conceptual framework also includes two direct pathways supported by observational studies linking SCPs to increased confidence in one's ability to manage care²¹ and changes in health behaviors.²²

Appendix C illustrates how we integrated survey items from the quantitative study with interview questions from the qualitative study based on our conceptual framework. Following integration, we reviewed all findings alongside the empirical literature to narrow

the broader conceptual framework to only include relevant outcomes and their possible causal linkages of interest.²³ Key findings from the initial quantitative and qualitative studies are presented independently, followed by the presentation of integrated findings using a narrative approach.^{24,25} The narrative approach provides intragroup comparisons of the results from the quantitative data that are either supported or challenged by text from the qualitative database.

Results

Summary of Quantitative Findings from Paper 1

We tested the full hypothesized structural model among HINTS respondents diagnosed with breast or colorectal cancer who received and completed treatment for their cancer. The model did not fit the data well, and the total and direct effects of SCPs to hypothesized proximal and distal outcomes were not significant. As a result, the receipt of an SCP was removed from the final structural model, and PCC served as the primary predictor. The results of the final structural model with the standardized regression coefficients are presented in Figure 2.

The overall fit statistics indicate that the model fit the data adequately well with a chi-square of 28.379 ($df = 16$, $p\text{-value} = 0.03$), RMSEA = 0.07, CFI = .88, and WRMR = 0.73. PCC had a significant direct effect on all outcomes except for health behaviors, and self-efficacy had a significant direct effect on physical health and health behaviors. Although we did not find a significant indirect effect of PCC on physical health via health self-efficacy, the p -value is approaching significance. To this end, the full structural model was tested in a larger sample of cancer survivors removing the restriction for the completion of active treatment. As shown in table 2, the point estimates remain approximately the same, but the p -

values for the indirect and direct effects reverse, indicating that health self-efficacy may completely mediate the relationship between PCC and physical health.

Summary of Qualitative Findings from Paper 2

Informed by our conceptual framework, we completed eight interviews with women diagnosed with breast and colorectal cancer who received cancer care at a large, urban, integrated safety-net hospital to elucidate experiences with and relevant outcomes of survivorship care planning. Specifically, we asked the women to recall their last treatment visit with their oncology care team as a proxy for the survivorship care planning visit. The women were also asked to discuss their experiences since completing active treatment to identify additional outcomes of survivorship and potential targets for intervention. We identified four overarching themes, which subsumed several categories (Table 3) and found that the women reported positive experiences with survivorship care planning and felt that their oncology care team prepared them for life post-treatment.

Based on the analysis of interview data, we characterized survivor-level outcomes into two broad categories - outcomes related to the process of survivorship care planning and outcomes following the survivorship care planning visit that require complex behavior change (Table 4).

Integration of Quantitative and Qualitative Data

Table 5 shows the distribution of sociodemographic, clinical, and cancer-related characteristics across the quantitative and qualitative samples. The interview sample of safety-net, female breast and colorectal cancer survivors was, on average, younger than the HINTS samples, 57 years of age versus nearly 64 years of age. In addition, a larger percentage of the interview sample was NH black (62.5) and uninsured (50.0). Finally, the majority of the interview sample completed active treatment in the last year (87.5), while the

majority of the HINTs samples completed treatment over a year ago. Table 6 provides the descriptive statistics for the variables of interest derived from our conceptual framework alongside an illustrative quote from semi-structured interview findings.

Receipt of a Survivorship Care Plan

Results from the quantitative data show that the majority of breast and colorectal cancer survivors did not receive an SCP, although the percentage of those reporting that they did receive an SCP is higher in survivors who were less than five years from active treatment. The female, safety-net breast and colorectal cancer survivors reported that they received and reviewed some form of written information with their oncology care team during the last treatment visit although they did not explicitly state that they received an SCP. The written information provided and reviewed by the oncology care team included information about upcoming appointments, who to contact with questions or concerns, instructions on how to take care of oneself based on the treatment received, and a list of possible warning signs and symptoms. The women did report that the written information they received did serve as a helpful reminder for upcoming appointments.

Patient-Centered Communication

The quantitative and qualitative findings suggest that breast and colorectal cancer survivors report positive communication experiences with their care teams. At a population level, both samples of breast and colorectal cancer survivors reported high overall scores of PCC with their healthcare providers. The interviews focused on the communication exchange with the oncology care team during the last treatment visit. The women reported positive communication experiences with their oncology care team and described how the oncology care team gave them all the information they needed to stay healthy post-treatment and communicated the information in a way that was timely, easy to understand, and responsive

to their needs and feelings. The women also reported that their oncology care team made it easy for them to ask questions and ensured that they understood the next steps in their care. However, the women did report gaps in communication mainly between oncology and non-oncology care teams. Specifically, the women reported that non-oncology care team members, such as primary care, were not always informed about their cancer treatment.

Perceived Self-Efficacy

Results from the quantitative data show that breast and colorectal cancer survivors, on average, feel confident in their ability to manage their overall health. For the qualitative study, we asked the women if they felt confident/good about their ability to take care of their health after cancer. The women stated that they felt good about their ability to take care of their health after cancer because their oncology care team provided them with the information (e.g., written information on what to look for and expect) and tools (e.g., supportive resources, referrals, scheduling upcoming appointments) they needed to be able to identify signs and symptoms of cancer recurrence.

Engaging in Lifestyle Behaviors

The quantitative data across both HINTS samples show the majority of cancer survivors are not meeting all recommended guidelines for healthy behaviors as outlined by the NCCN, especially for minutes of physical activity. We asked the women specific questions about their health behaviors such as minutes of physical activity per day, servings of fruits/vegetables intake per day, and tobacco use. The majority of women were not meeting the recommended guidelines. However, the women emphasized the importance of engaging in healthy behaviors and reported that they were currently engaging in at least one behavior. They also stated that despite oncology care teams and other providers communicating the importance of engaging in healthy behaviors, this did not always translate

to the desired behavior due to a number of barriers, such as declines to physical health due to other chronic conditions and a lack of social support. Despite these challenges, a couple of women described how being diagnosed with cancer gave them the motivation they needed to stay healthy after cancer treatment and several women emphasized the importance of social support from friends, family, and oncology care teams in helping with daily living activities, providing ongoing encouragement, practical assistance, and referrals to resources.

Physical Health

The quantitative findings show similarities across both samples of breast and colorectal cancer survivors. Specifically, both samples, on average, rated their overall health good, despite being overweight and having at least one chronic condition in addition to cancer. Findings from the qualitative data may provide glimpses into this perception of overall health. The women primarily characterized their health after cancer treatment as the presence or absence of physical symptoms resulting from cancer and its treatment. The women stated that the absence of physical symptoms also served as an indicator of doing well after cancer because they were able to do the things they used to do before cancer treatment. However, the women also acknowledged that they continued to experience symptoms related to their other chronic conditions that at times served as a barrier to engaging in activities that promoted overall health, such as exercise and diet.

Additional Qualitative Insights

Findings from the qualitative study provided additional insights that were not explored in the quantitative analysis due to limitations in the HINTS datasets. In addition to communicating to the women the next steps in care, the women emphasized the role of their oncology care team in setting up future appointments, ordering upcoming labs/radiology, and making referrals to non-oncology providers and resources as part of the survivorship care

planning process. The women also acknowledged the importance of doing “*exactly what the doctors and them tell me to do*” to ensure that the cancer does not spread or return. In addition, the women described the role of social support and motivation in managing their health after cancer treatment. Specifically, the women discussed how the cancer diagnosis served as an intrinsic motivator to stay healthy after cancer and that a recommendation from an oncology care team member also served as an extrinsic motivator to engage in cancer surveillance and healthy lifestyle behaviors. The women also described the importance of having social support from family, friends, and oncology care team members to assist with daily living activities, encourage engagement in healthy lifestyle behaviors, and provide ongoing information and support.

Modifications to Survivorship Care Planning Frameworks

Based on the integration of findings, we propose a framework for survivorship care planning research that builds upon existing models by depicting the direct and indirect pathways linking the process of survivorship care planning to key survivor-level outcomes (Figure 3). This framework is based on the survivor’s perspective of survivorship care planning and the experience following the completion of active treatment. This framework does not consider the influence of system- (i.e., organizational structure, capacity) and/or provider-level factors (i.e., individual-level factors) on survivor-level outcomes.

We start on the left side of the model with the survivorship care planning visit – defined as the last treatment visit. Based on our findings, the communication experience between the oncology care team and the survivor is central to the survivorship care planning process and should encompass the six core functions of PCC. The receipt of an SCP may assist with the exchange of information - one domain of PCC – but does not replace the

communication experience. To this end, PCC is the central outcome of the survivorship care planning visit that directly impacts proximal outcomes of the communication exchange including knowledge in survivorship care and satisfaction with care and information received. Effective PCC may also directly result in changes in perceived self-efficacy to identify signs and symptoms of cancer recurrence and management in overall health. In most cases, PCC is likely to impact perceived self-efficacy indirectly via knowledge in survivorship care. Insights from the interviews identified that the oncology care team is also responsible for coordinating key cancer surveillance activities and should communicate and coordinate their plans with non-oncology care team members, such as primary care. Therefore, another outcome of the survivorship care planning process from a survivors' perspective may be perceived care coordination.

Our framework makes an important distinction between outcomes specific to the process of survivorship care planning versus outcomes that require complex behavior change. Insights from the qualitative study suggest that the survivorship care planning visit alone is unlikely to result in changes to complex behaviors. Based on findings from the qualitative study, we identified determinants and psychological mechanisms of behavior change derived from health behavior theory. Perceived self-efficacy is the primary explanatory construct of prominent health behavior theories, such as Social Cognitive Theory, due to its ability to predict and explain who is (or is not) motivated to perform health-related behaviors.^{26,27} To this end, our conceptual framework depicts a direct pathway linking perceived self-efficacy to engage in and overcome barriers to engaging in adherence behaviors. Beyond direct links between self-efficacy and adherence behaviors, health behavior theories suggest that any number of motivational factors can lead people to say they “can” or “cannot” perform

specific adherence behaviors (e.g., liking/disliking exercise, expected outcomes of performing adherence behaviors, and expected outcome of prioritizing adherence behaviors over other competing demands).²⁸ Our qualitative findings support the inclusion of a direct pathway linking motivation (intrinsic/extrinsic) to adherence behaviors, as well as a direct pathway from perceived social support to adherence behaviors, in which social support may influence engagement of adherence behaviors through practical assistance, emotional, and informational support.²⁹ Based on our findings and substantial evidence in the literature supporting the importance of adherence behaviors to overall health, we have included a direct pathway linking adherence behaviors to overall physical health and quality of life. Finally, our model recognizes the influence of individual-level sociodemographic, clinical, and cancer-related characteristics on survivor-level outcomes across the survivorship continuum.

Discussion

Survivorship care plans remain an integral component of cancer survivorship care and are regarded as a core measure of the American Society of Clinical Oncology Quality Oncology Practice Initiative despite limited empirical evidence supporting what SCPs can reasonably be expected to change.^{1,30} Optimum survivorship care encompasses cancer-specific surveillance, supportive care for late and long-term effects, management of other chronic conditions, general preventive care, and supportive care.³¹ These components of care are unlikely to be achieved in a single document. Yet, the majority of research continues to place priority on improving the content, use, and delivery of SCPs rather than on the survivorship care planning process. Our study is unique in that we used an adaptive mixed-methods approach to provide a high-level synthesis of data from various sources and populations to better understand the process of survivorship care planning and to identify

more appropriate survivor-level outcomes. Overall, our study supports that SCPs cannot stand alone in improving survivor-level outcomes if there are no mechanisms in place to implement the plan's recommendations. For example, most oncologists do not possess the skills to counsel on health behaviors. As such, guideline recommendations for cancer surveillance and healthy lifestyle behaviors incorporated into the survivorship care planning process are meaningless unless the appropriate supportive care resources and interventions are integrated into the standard workflow of cancer care programs.^{12,31,32}

Our study is unique in that it goes beyond examining survivorship care planning from a health services perspective and focuses on the survivor's experience as a key stakeholder in the process. Most processes of survivorship care planning focus on how various stakeholders (providers, nurses, administrators) operate and interact within the larger health care system and the role expectations associated with those involved in the delivery and coordination of survivorship care.^{13,33,34} Results from this study provide a glimpse into the potential gaps in the survivorship care planning process and emphasize the need for patient-centered approaches to survivorship care. First, effective PCC by the oncology care team with the survivor is essential to delivering high-quality survivorship care planning and involves giving and explaining information in a way that is easy to understand, eliciting questions and concerns, ensuring that the survivor understands the next steps in their care, and being responsive to negative emotions and feelings of uncertainty.^{1,35} Delivering an SCP may help facilitate the exchange of information, but it is not a replacement for PCC. Second, oncology care teams are also responsible for coordinating cancer surveillance activities, and engaging non-oncology care team members in the survivor's care. Our qualitative findings support that gaps remain in survivorship care delivery due to poor coordination and inadequate

communication between members of multi-disciplinary care teams (i.e., between oncologist and primary care providers).⁴ Finally, previous frameworks of survivorship care planning assume that the process alone is sufficient enough to drive complex behavior changes at the survivor-level. However, our findings suggest that this is not the case and emphasize the need to understand the influence of individual-level factors on key survivorship outcomes and supports the inclusion of behavioral science theory into existing frameworks of survivorship care to help predict and explain behavior change.

The basis for many barriers to providing high-quality survivorship care planning is the lack of evidence regarding best practices that are likely to result in improved survivor-level outcomes.^{1,36} Although several models of survivorship care have been proposed to address the gaps we identified in this study; few studies have described the process or outcomes of these models.^{33,34,37} The use of implementation and behavioral science theory may provide new insights into the development and planning of comprehensive survivorship care models. Behavioral science can assist with linking relevant causal factors of a behavior to appropriate model components and provides valuable insight into the underlying mechanisms driving change in survivor-level outcomes.³⁷ Implementation science is dedicated to promoting the uptake of survivorship care models given the complex set of conditions and factors potentially impacting the effectiveness of models on outcomes.³⁸ Using frameworks derived from behavioral and implementation science theory, such as Intervention Mapping, may help to reduce gaps identified in this study by assisting researchers and planners in clinical settings with systematically planning strategies aimed at achieving realistic and relevant outcomes of their survivorship care planning model.³⁹

Strengths and Limitations

Our study had several limitations. In addition to limitations previously described in papers one and two, a notable limitation of this study is that we did not collect data from the same sample – the most ideal approach in mixed methods research. However, collecting data from the same sample was challenging in this instance for a number of reasons. First, few frameworks of survivorship care planning exist, and the generation of relevant survivor-level outcomes at a population level is relatively unknown. Second, there is lack of items related to survivorship care planning in national-level datasets and a lack of validated measures to assess hypothesized survivor-level outcomes more broadly. Thirdly, recruiting from a single safety-net healthcare system limits the number of cancer cases resulting in small sample sizes and insufficient power to test relationships. Finally, limitations in the HINTS dataset did not allow for testing of the modified conceptual framework at a population level, and we were unable to test meaningful differences in outcomes by subgroups.

Despite these limitations, our study has many strengths. The use of an adapted mixed methods approach brings together the strengths and weaknesses of quantitative and qualitative data, and the utilization of deductive and inductive approaches deepened our understanding of the topic. In addition, data from various data sources and populations provided a high-level synthesis of the problem that could not be described within a single population or setting. Our study was also guided by a clear conceptual framework derived from clinical and behavioral science to facilitate the integration of findings. The use of a conceptual framework also assisted with the identification of potential targets for future intervention and may inform measurement development. Although findings from this paper limit our ability to generalize to other settings, the overall synthesis of results provides

important information to inform recommendations and hypothesis-generating direction for future research.

Recommendations and Future Research

Based on the information summarized above, we recommend consideration of several areas for future research on survivorship care.

1. Providing high-quality survivorship care requires an infrastructure in which comprehensive, integrated care, according to guidelines, can be delivered. Future research should continue to describe the setting in which care planning occurs, the participants involved in the planning process, and the structures and processes in place to support quality transitional care.
2. Our findings support research agendas shifting away from examining the effectiveness of SCPs in isolation. Future research should continue to focus on strategies to improve key elements of the survivorship care planning process such as communication and care coordination, as well as consider the influence of individual-level characteristics on survivor-level outcomes across the survivorship continuum.
3. Future studies should move beyond thinking about survivorship from a health services delivery lens and begin incorporating implementation and behavioral science theory to understand the underlying mechanisms of the survivorship care planning process. Theory-based approaches will help to explain how and why a process or model of survivorship care succeeds or fails in different settings and populations.
4. Researchers and cancer care programs need to systematically plan for implementation and consider the complex set of conditions and factors that may influence the

effectiveness of their models of survivorship care and give greater consideration to the types of outcomes that components of their survivorship model are able to change.

Conclusion

As the population of cancer survivors continues to grow, conducting research to address knowledge gaps and barriers in survivorship care will become even more urgent. Our study builds upon the existing knowledge base by identifying gaps in the current conceptualization of survivorship care planning frameworks and informs the selection of and measurement of relevant outcomes of the survivorship care planning process. Future studies should continue to explore the most appropriate outcomes of survivorship care planning and evaluate whether group differences in outcomes are observed. Finally, findings from this study emphasize the need for future studies grounded in implementation and behavioral science theory to assist researchers and cancer care programs in planning for and implementing models of survivorship care that address realistic and relevant outcomes at a survivor-level.

Tables and Figures for Paper 3

Tables for Paper 3

Table 1. Data Sources with corresponding breast and colorectal cancer survivor populations	
Data Sources	Survivor Population
Health Information National Trends Survey	National-level estimates of breast and colorectal cancer survivors
Interview Transcripts	Safety-net, female, breast and colorectal cancer survivors with multiple chronic conditions

Table 2. Standardized Total, Direct, and Indirect Effects				
	HINTS Sample 1 (N = 212)		HINTS Sample 2 (N = 273)	
	<i>b</i> (SE)	<i>p</i> -value	<i>b</i> (SE)	<i>p</i> -value
Patient-Centered Communication to Physical Health				
Total effect	0.33 (0.12)	0.01	0.34 (0.11)	<0.01
Indirect effect	0.12 (0.05)	0.02	0.11 (0.06)	0.06
Direct effect	0.22 (0.12)	0.08	0.23 (0.12)	0.05
Notes: Abbreviations: PCC = Patient-Centered Communication; PH = Physical Health				
Sample 1 includes those diagnosed with breast or colorectal cancer who have received and completed treatment for cancer.				
Sample 2 includes those diagnosed with breast or colorectal cancer.				

Table 3. Summary of Themes and Domains	
Themes	Domains
Survivorship Care Planning	
	Written and Verbal Information Exchange
	Ensuring patient understanding
	Eliciting Questions and Concerns
Patient-Provider Communication	Making Decisions
	Responsiveness
	Responding to Patient Needs
	Gaps in communication
Oncology Care Team Responsibilities	Setting up appointments
	Scheduling/Ordering labs/radiology
	Referring to non-oncology providers and resources
Post-Survivorship Care Planning	
	Physical Health
	Mental Health
Post-treatment experience	Unexpected Experiences
	Return to pre-cancer function
	Cancer surveillance behaviors
Adherence Behaviors	Healthy lifestyle behaviors
	Barriers to adherence behaviors
Self-efficacy	Barriers to managing health

Table 4. Relevant Survivor-Level Outcomes	
Outcomes of the survivorship care planning process	Outcomes of Survivorship
Patient-Centered Communication	Engagement in Adherence Behaviors <ul style="list-style-type: none"> • Adhering to guidelines for cancer surveillance and healthy living after cancer
Knowledge of survivorship care	Perceived self-efficacy ^a
Satisfaction with information received/overall care	Motivation to engage in adherence behaviors
Perceived care coordination	Perceived social support (informational/emotional)
Perceived self-efficacy ^a	Patient-reported outcome measures
Perceived social support (informational/emotional)	

Table 5. Sample Sociodemographic, Clinical, and Cancer Characteristics			
	HINTS Sample 1 (N = 212)	HINTS Sample 2 (N = 42)	Interview Sample (N=8)
	N (Weighted % ^a)	N (Weighted % ^a)	N (%)
Age (mean)	63.6	63.7	57.0
Race/Ethnicity			
NH White	132 (82.1)	30 (82.8)	3 (37.5)
NH Black	32 (11.0)	12 (17.2)	5 (62.5)
Other	26 (6.9)	-	-
Insurance Status			
Yes (Medicare/Medicaid)	199 (95.0)	39 (94.7)	4 (50.0)
No Uninsured/Financial Assistance	10 (5.0)	2 (5.3)	4 (50.0)
# of Chronic Condition in addition to cancer			
0	29 (18.4)	-	
1-2	117 (58.7)	28 (77.14)	6 (75.0)
>2	59 (22.9)	14 (22.9)	2 (25.0)
Cancer Site			
Breast	158 (73.8)	34 (81.1)	5 (62.5)
Colorectal	54 (26.2)	8 (18.9)	3 (37.5)
Months since end of initial treatment			
< 1 year	19 (10.0)	10 (33.4)	7 (87.5)
1-5 years	57 (23.1)	32 (66.7)	1 (12.5)
> 5 years	136 (66.9)	-	
Still in treatment	-	-	

Table 6. Integration of Qualitative and Quantitative Data			
	HINTS Sample 2 (N = 212)	HINTS Sample 3 (N=42)	Interview Sample (N=8)
	Mean (SD) or N (Weighted % ^a)		Illustrative Quote
Receipt of SCP			
Yes	86	21	<i>They [oncology providers] provided me with the information. Not just tell me, they also gave me the uh the printout of what I needed to do and how I needed to take care of myself and what to expect” (49 year old, NH black, stage III colorectal cancer survivor).</i>
No	(38.1) 123 (61.9)	(48.4) 21 (51.6)	
Patient-Centered Communication ^b	20.7 (0.3)	20.4 (0.9)	<i>She’s [oncologist] given me all the tools that I need to be able to take care of myself as best I can. I mean like I said, she’s got all these appointments scheduled for me, all this lab work scheduled for me and she’s explained the importance of all of these things...Well, like I’ll talk to the oncologist and then she’ll say- do you understand?- and I’ll be like- Yes. And she’ll say- Okay, well explain to me what I told you (54 year old, NH white, stage I breast cancer survivor).</i>
Health Self- Efficacy ^c	3.7 (0.1)	3.8 (0.1)	<i>I think I can take care of it by catching it, by watching out and stuff like that. So I’m aware of all that stuff now and if I feel different things or see different things (56 year old, NH white, stage II breast cancer survivor).</i>
Lifestyle Behaviors			
Aerobic physical activity			<i>I actually exercise daily. Uh-huh, about 30 minutes. I walk (59 year old, NH black, stage III breast cancer survivor).</i>
0 min/week	84	20	<i>I’d say [I walk] about 10 to 15 minutes a day (49 year old, NH black, stage III colorectal cancer survivor).</i>
0-149 min/week	(39.6)	(50.4)	
>150 mins/week	76 (32.7) 51 (27.7)	12 (30.7) 10 (18.9)	
Fruit/Vegetable Intake			<i>Um, I eat four actually [servings a day]. Mostly fruit (59 year old, NH black, stage III breast cancer survivor).</i>
< 3-5 servings/day	84	17	<i>Oh some days I don’t get any, but I miss it when I don’t, unless you consider tomato and lettuce on my hamburger...I would say at least one serving of a type of vegetable a day um I try to. Sometimes the day goes weird and I don’t (65 year old, NH white, stage I breast cancer survivor).</i>
> 3-5 servings/day	(33.1) 128 (66.9)	(40.6) 25 (59.4)	
Tobacco Use			<i>I’m working to get off these cigarettes and I got stuff, you know, I buy and everything because I want to get off them cigarettes (70 year old, NH black, stage I breast cancer survivor).</i>
Never	128	22	<i>Yeah and I said at least I’m down to this where I used to be three cartons a month. I’m down to one carton and five packs. I mean give me some credit (56 year old, NH white, stage II breast cancer survivor).</i>
Former or Current	(62.0) 82 (38.0)	(46.8) 20 (53.2)	
Physical Health			
BMI	28.7 (0.9)	32.3 (2.7)	<i>I’ve started to lose some weight now. Let’s see- yeah, I’m just making healthy choices food wise and exercise wise or</i>

Table 6. Integration of Qualitative and Quantitative Data				
Number of Chronic Conditions	1.7 (0.1)	1.9 (0.2)	movement wise (65 year old, NH white, stage I breast cancer survivor). Well, I got a lot of other problems other than that so I still stay tired a lot... Yeah from my- and my bones hurt and stuff like that, but it's not from the cancer. It's from everything else that's wrong with me (56 year old, NH white, stage II breast cancer survivor).	
Self-reported Physical Health ^c	3.1 (0.1)	2.9 (0.2)	Um, gratefully the fatigue is lessening, and I'm able to get on with doing things that I haven't been able to commit to doing because I didn't know how long I would be fatigued. From the beginning treatment, I can't think of the name of that particular drug in that chemo, a side effect of it has been neuropathy in my fingers and toes. So that's still lingering, but I don't know if I'm just getting used to it or if it's lessening, you know, from time to time I don't even think about it and then like right now it's tingling as I'm- oh, yeah it has that tingling effect in my fingers kind of thing (65 year old, NH white, stage I breast cancer survivor).	

Figure for Paper 3

Figure 1. Conceptual Framework depicting hypothesized pathways linking SCPs to survivor-level outcomes.

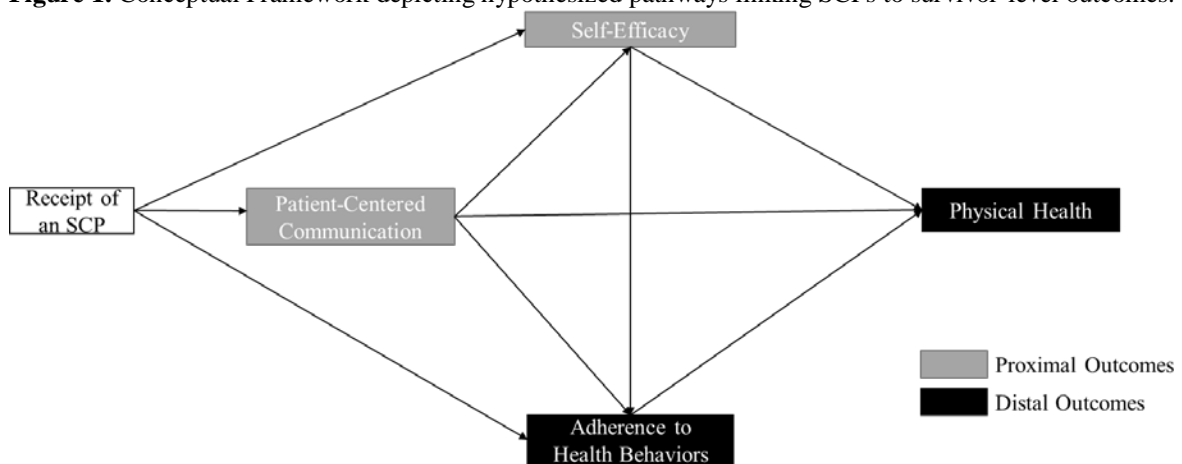


Figure 2. Standardized results for the final structural model.

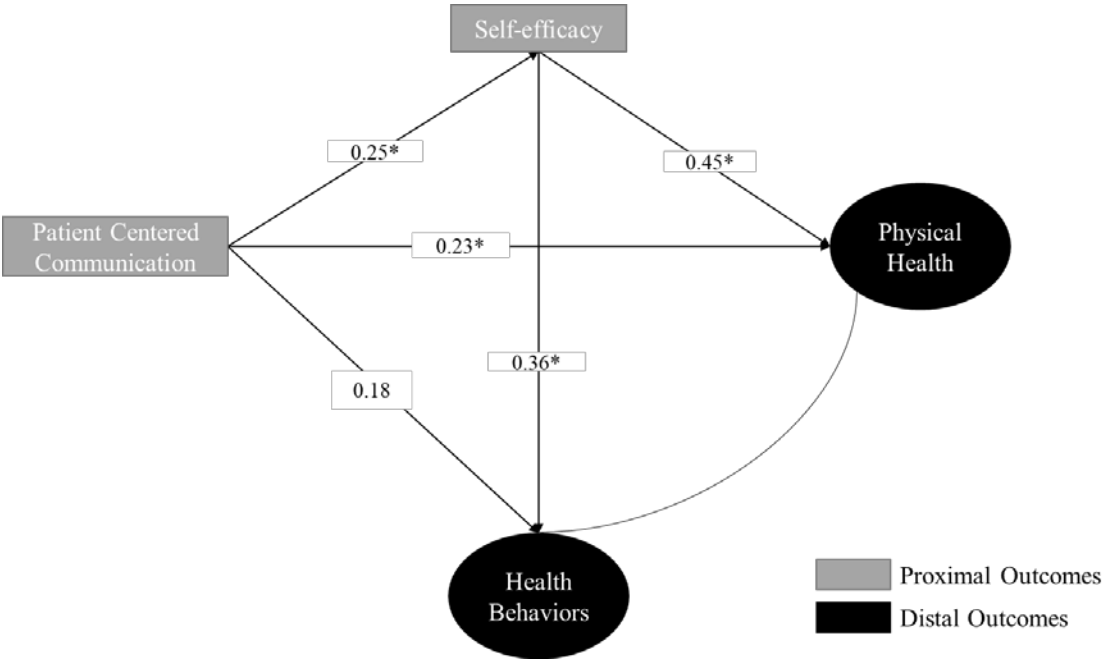
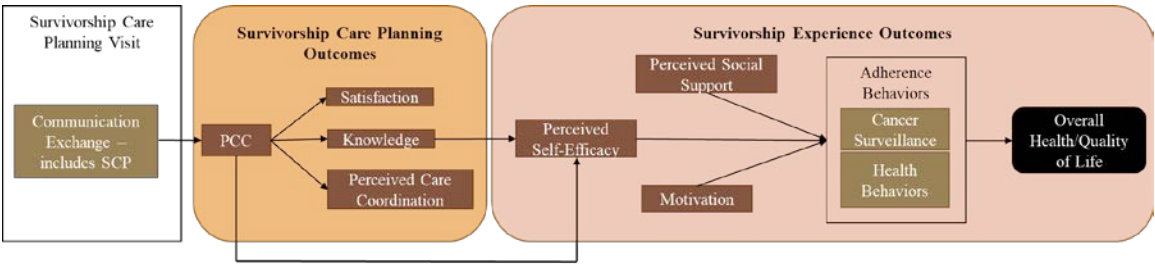


Figure 3. Modified Conceptual Framework for Survivorship Care Planning



- Sociodemographic, clinical, and cancer-related characteristics may facilitate or hinder outcomes across the survivorship continuum.
- Individual-level determinants should be measured towards a specific behavior

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CONCLUSION

As the population of cancer survivors continues to grow, conducting research to address knowledge gaps and barriers in survivorship care will become even more urgent. This dissertation sought to understand the relationship between the receipt of an SCP on key survivor-level outcomes of survivorship care planning. Paper one tested a conceptual framework among a nationally representative sample of breast and colorectal cancer survivors and found that SCPs did not have a total or direct effect on key survivor-level outcomes. Rather, we identified PCC and health self-efficacy as potential target areas for future interventions that may influence long-term health outcomes. These findings emphasized the need to move beyond studies that look at SCPs in isolation and instead conduct research in which SCPs are embedded in evaluating the effectiveness of different models of survivorship care.^{33,44}

The second paper focused on the experiences with the process of survivorship care planning among safety-net breast and colorectal cancer survivors. Understanding the first-hand experiences of these survivors provided meaningful insight into the complexities of measuring the effectiveness of survivorship care models and emphasizes the need for ongoing assessment of outcomes that consider implications of cancer amidst other chronic conditions, as well as the need to assess individual-level determinants of behavior change. Paper three provided a high-level synthesis of all dissertation findings and builds upon the existing knowledge base by identifying gaps in the current conceptualization of survivorship care planning frameworks and informs the selection of and measurement of relevant outcomes of the survivorship care planning process.

Strengths and Limitations

Although these findings represent a significant contribution to the literature, this dissertation has a number of limitations. The cross-sectional nature of the HINTS dataset limits our ability to make causal inferences from our findings or account for the timing of the exposure, mediators, and outcome variables. HINTS is self-report and could potentially result in under- or over-reporting and recall bias. The variables and responses coded in the HINTS dataset are also limited in capturing the complexity of outcomes or the relationship among variables. In addition, the sample size of breast and colorectal cancer survivors in HINTS limited our ability to test meaningful differences in the structural model by subgroups. Finally, limitations in the HINTS dataset did not allow for testing of the modified conceptual framework at a population level.

The analysis of qualitative data does not allow for causal inference and cannot be generalized to other settings caring for safety-net breast and colorectal survivors. The size of our interview sample limited our ability to look at other factors such as race/ethnicity, socioeconomic, clinical, and cancer-related characteristics in a meaningful way. Our findings may also be limited by recall bias given that survivors with multiple chronic conditions may have trouble recalling who they saw, when, and what was discussed. Social desirability may be another limitation since safety-net survivors may feel the need to speak positively about the oncology care team to continue receiving quality care, although candid reports in our study suggest this was unlikely, nonetheless social desirability was not measured.

In addition to limitations previously described, a notable limitation is that we did not collect data from the same sample – the most ideal approach in mixed methods research. However, collecting data from the same sample was challenging in this instance for a number of reasons. First, few frameworks of survivorship care planning exist, and the generation of relevant

survivor-level outcomes at a population level is relatively unknown. Second, there is lack of items related to survivorship care planning in national-level datasets and a lack of validated measures to assess hypothesized survivor-level outcomes more broadly. Thirdly, recruiting from a single safety-net healthcare system limits the number of cancer cases resulting in small sample sizes and insufficient power to test relationships.

Despite these limitations, this dissertation research has notable strengths. The quantitative findings are useful for exploratory analyses to generate hypotheses and explore the use of SEM in epidemiological studies. The HINTS dataset is also one of the few publically available datasets with comprehensive measures associated with survivorship care with survey items applicable to one's health and healthcare experience more broadly. The qualitative findings allowed for an in-depth understanding of subtleties and complexities around the survivorship care planning process and provided perspectives of safety-net populations that have been underrepresented in research to date. In addition, the qualitative sample was representative of the safety-net breast and colorectal cancer survivor population at a large, urban setting and is one of the few studies to elucidated perspectives among survivors across multiple cancer sites. The qualitative findings may help to inform quality improvement targets for Parkland and serve to generate hypotheses that may be tested in future target interventions and studies.

The use of an adapted mixed methods approach brings together the strengths and weaknesses of quantitative and qualitative data, and the utilization of deductive and inductive approaches deepened our understanding of the topic.¹⁰⁹ In addition, data from various sources and populations provided a high-level synthesis of the problem that could not be described within a single population or setting. This dissertation was also guided by a clear conceptual framework derived from clinical and behavioral science to facilitate the integration of findings.

The use of a conceptual framework also assisted with the identification of potential targets for future intervention and may inform measurement development. Although findings from this dissertation is limited in the ability to generalize to other settings, the overall synthesis of results provides important information to inform recommendations and hypothesis-generating direction for future research.

Recommendations and Future Research Directions

Based on the information summarized above, we recommend consideration of several areas for future research on survivorship care. These findings support research agendas shifting away from examining the effectiveness of SCPs in isolation and advocate for research that continues to identify and refine the most relevant survivor-level outcomes of survivorship care planning across diverse clinical settings and evaluates whether group differences in outcomes are observed.^{32,33,44}

Providing high-quality survivorship care requires an infrastructure in which comprehensive, integrated care, according to guidelines, can be delivered. There is a need to describe the setting in which care planning occurs, the participants involved in the planning process, and the structures and processes in place to support quality transitional care. Future research should continue to focus on strategies to improve key elements of the survivorship care planning process such as communication and care coordination, as well as consider the influence of individual-level characteristics on survivor-level outcomes across the survivorship continuum.

These findings support the need to move beyond thinking about survivorship from a health services delivery lens and begin incorporating implementation and behavioral science theory to understand the underlying mechanisms of the survivorship care planning process. Theory-based approaches will help to explain how and why a process or model of survivorship

care succeeds or fails in different settings and populations. Researchers and cancer care programs need to systematically plan for implementation and consider the complex set of conditions and factors that may influence the effectiveness of their models of survivorship care and give greater consideration to the types of outcomes that components of their survivorship model are able to change.

APPENDICES

Appendix A: HINTS Survey Items and Analytic Categories

Domain	Item(s)	Response scale(s)	Analysis categories
Receipt of Care Plan	<i>“Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatment you received for your cancer?”</i>	<i>Yes</i> <i>No</i>	1. Received care plan 2. Did not receive a care plan
Patient-Centered Communication	<i>How often did the doctors, nurses, or other health care professionals you saw during the past 12 months do each of the following: (1) Give you a chance to ask all the health-related questions you had? (Fostering Healing Relationships) (2) Give the attention you needed to your feelings and emotions? (Responding to emotions) (3) Involve you in decisions about your health care as much as you wanted? (Making decisions) (4) Make sure you understood the things you needed to do to take care of your health? (Enabling self-management) (5) Explain things in a way you could understand? (Exchanging Information) (6) Help you deal with feelings of uncertainty about your health or healthcare? (Managing uncertainty).</i>	<i>Always</i> <i>Usually</i> <i>Sometimes</i> <i>Never</i>	Continuous overall score (Range 9-24) with higher scores indicating higher levels of PCC.
Health Self-Efficacy	<i>“Overall, how confident are you about your ability to take good care of your health?”</i>	<i>Completely confident</i> <i>Very confident</i> <i>Somewhat confident</i> <i>A little confident</i> <i>Not confident at all</i>	Continuous overall score (Range 1 -5) with higher scores indicating higher levels of self-efficacy.
Aerobic physical activity	<i>“In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, and swimming at a regular pace?”;</i> <i>“On the days that you do any physical activity or exercise of at least moderate intensity, how long do you typically do these activities?”</i>	0-7 days a week; Free response	1. 0 Mins MVPA/week 2. Between 1-149 min MVPA/week 3. 150 mins+ MVPA/week
Fruit consumption	<i>“About how many cups of fruit (including 100% pure fruit juice) do you eat or drink each day?”</i> <i>1 cup of fruit could be:</i> <i>1 small apple; 1 large banana; 1 large orange;</i> <i>8 large strawberries; 1 medium pear;</i> <i>2 large plums; 32 seedless grapes; 1 cup (8 oz.) fruit juice; ½ cup dried fruit; 1 inch-thick wedge of watermelon”</i>	<i>None</i> <i>½ cup or less</i> <i>½ cup to 1 cup</i> <i>1 to 2 cups</i> <i>2 to 3 cups</i> <i>3 to 4 cups</i> <i>4 or more cups</i>	(Fruit and vegetable consumption combined to create one variable) 1. Consistent with recommended guidelines: eating between 1-2 cups of fruit or more daily

Domain	Item(s)	Response scale(s)	Analysis categories
Vegetable consumption	<p><i>“About how many cups of vegetables (including 100% pure vegetable juice) do you eat or drink each day?”</i></p> <p><i>1 cup of vegetables could be: 3 broccoli spears; 1 cup cooked leafy greens; 2 cups lettuce or raw greens; 12 baby carrots; 1 medium potato; 1 large sweet potato; 1 large ear of corn; 1 large raw tomato; 2 large celery sticks; 1 cup of cooked beans”</i></p>	<p><i>None, ½ cup or less, ½ cup to 1 cup 1 to 2 cups 2 to 3 cups 3 to 4 cups 4 or more cups</i></p>	<p>and between 2-3 cups of vegetables or more daily (> 3-5 servings per day)</p> <p>2. Not consistent with recommended guidelines: less than the above levels (< 3-5 servings per day)</p>
Tobacco use	<p><i>“Have you smoked at least 100 cigarettes in your entire life?”</i></p> <p><i>“How often do you smoke cigarettes now?”</i></p>	<p><i>Yes No</i></p> <p><i>Every day Some days Not at all</i></p>	<p>1. Current</p> <p>2. Former</p> <p>3. Never</p>
Self-Reported Health	<p><i>“In general, would you say your health is...”</i></p>	<p><i>Excellent Very Good Good Fair Poor</i></p>	<p>Continuous overall score (Rang 1-5) with higher scores indicating higher level of self-reported health</p>
BMI	<p><i>Self-reported height and weight</i></p>	<p><i>Free Response</i></p>	<p>Derived continuous measure from HINTS</p>
Number of Chronic Conditions	<p><i>Has a doctor or other health professional ever told you that you had any of the following medical conditions: Diabetes or high blood sugar Hypertension or high blood pressure A heart condition Chronic lung disease Arthritis or rheumatism.</i></p>	<p><i>Yes No</i></p>	<p>Items summed to create a continuous measure</p>

Appendix B: Semi-Structure Interview Items

Note that this interview guide is elucidative of three major topics and that all questions may not be asked to every patient.

Tell me what it has been like since you finished your cancer treatment.

Topic: Survivorship Care Planning Visit

- 1.) Did you see your cancer doctor, nurse, or other health professional at your last visit when you finished treatment?
- 2.) What did your doctor/nurse talk to you about during the visit?
 - a. Did the doctor/nurse go over the papers with you during the visit?
- 3.) When you finished your treatment, did you get any papers during your last visit?
 - a. What did it cover?
 - b. What did you find most helpful?
 - c. What did you find to be least helpful?
 - d. Was there anything missing?
- 4.) Tell me how the papers you got from your doctor/nurse during that last visit had an effect on how you speak with your doctor?

PCC – Thinking about the last visit

- 1.) What role does speaking with your doctor/nurse play when it comes to your overall health?
- 2.) What can doctors/nurses do to make it easier for you to speak with them about your needs?
- 3.) Did your doctor/nurse make you feel comfortable asking questions? (Fostering Healing Relationships)
- 4.) Did your doctor make sure you understood the things you needed to do to take care of your health after cancer treatment? (Exchanging Information)
- 5.) Did your doctor give you all the information or resources you need to help you make decisions? (Making Decisions)
- 6.) Did your doctor/nurse make sure that you understood the next steps in your health after cancer treatment? (Self-Management)
- 7.) Cancer patients often face uncertainties about life after cancer treatment. For example, patients may not know what will happen, if the cancer will come back, or who to go to for help. How well did your doctor/nurse help you deal with the uncertainties about your cancer? (Managing Uncertainty)
- 8.) Did your doctor/nurse talk with you about how to cope with any fears, stress, and other feelings you may have after cancer treatment? (Responding to Emotions)
- 9.) How important is it to you that your doctor/nurse speak with you in a way that lines up with your needs after cancer treatment?

Topic: Post Survivorship Care Planning Visit – Focus on outcomes

Doctors and hospitals try to address things that they feel are important to your health after finishing cancer treatment but I am interested in what you feel is important to your health after cancer treatment.

- 1.) When it comes to your health, how do you know that you are doing well after cancer treatment?
- 2.) If you had to choose the most important thing you could do to stay healthy, what would it be and why?
 - a. What can doctors/nurses do to help you stay healthy after cancer treatment?

Health Self-Efficacy

- 1.) Do you feel good about your ability to take good care of your health after cancer treatment?
 - a. Why?
 - b. What would make you feel better about taking care of your health?
- 2.) How important is it to you to feel good about your ability to take good care of your health?
- 3.) What can doctors/nurses do to make you feel better about taking care of your health?

Lifestyle Behaviors

- 1.) How many minutes of exercise do you get per week?
- 2.) How many servings of fruit and vegetables do you eat per day?
- 3.) Do you smoke?
- 4.) Did you see a doctor within the last year for a routine check-up?
- 5.) How important is it to you to have a healthy lifestyle (exercise, eat right, not smoke, and see a doctors regularly)?
- 6.) What can doctors/nurses do to help you make changes to your lifestyle?

Topic: Experience with Survivorship

- 1.) Is there anything you wish the doctor would have told you?
- 2.) Was there anything that surprised you or that you didn't expect?
- 3.) Is there anything else you would like to tell me about your health after cancer treatment that we did not talk about?

Appendix C: Integration of Quantitative and Qualitative Findings

Relationships between Domains and Data Sources		
Domain	HINTS Survey Item(s)	Semi-Structure Interview Question
Receipt of Care Plan	“Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatment you received for your cancer?”	1.) Did you get any papers before you left? a. What did it cover? Was it helpful? Was there anything missing? How have you used the information since the visit?
Patient-Centered Communication	How often did the doctors, nurses, or other health care professional you saw during the past 12 months do each of the following: (1) Give you a chance to ask all the health related questions you had? (Fostering Healing Relationships) (2) Give the attention you needed to your feelings and emotions? (Responding to emotions) (3) Involve you in decisions about your health care as much as you wanted? (Making decisions) (4) Make sure you understood the things you needed to do to take care of your health? (Enabling self-management) (5) Explain things in a way you could understand? (Exchanging Information) (6) Help you deal with feelings of uncertainty about your health or healthcare? (Managing uncertainty).	1.) Did your doctor/nurse make you feel comfortable asking questions? (Fostering Healing Relationships) 2.) Did you doctor make sure you understood the things you needed to do to take care of your health after cancer treatment? (Exchanging Information) 3.) Did your doctor give you all the information or resources you need to help you make decisions? (Making Decisions) 4.) Did your doctor/nurse talk with you about how to cope with any fears, stress, and other feelings you may have after cancer treatment? (Responding to Emotions) 5.) Did your doctor/nurse make sure that you understood the next steps in your health after cancer treatment? (Self-Management) 6.) Cancer patients often face uncertainties about life after cancer treatment. For example, patients may not know what will happen, if the cancer will come back, or who to go to for help. How well did your doctor/nurse help you deal with the uncertainties about your cancer? (Managing Uncertainty)
Health Self-Efficacy	“Overall, how confident are you about your ability to take good care of your health?”	1.) Do you feel good about your ability to take good care of your health after cancer treatment? Why? 2.) What would make you feel better about taking care of your health?
Aerobic physical activity	“In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, and swimming at a regular pace?”; “On the days that you do any physical activity or exercise of at least moderate intensity, how long do you typically do these activities?”	1.) How many minutes of exercise do you get per week?
Fruit/Vegetable consumption	“About how many cups of fruit (including 100% pure fruit juice) do you eat or drink each day? “About how many cups of vegetables (including 100% pure vegetable juice) do you eat or drink each day?	1.) How many servings of fruit and vegetables do you eat per day?

Relationships between Domains and Data Sources		
Tobacco use	“Have you smoked at least 100 cigarettes in your entire life?”	1.) Do you smoke?
Physical Health	“In general, would you say your health is...”	1.) When it comes to your health, how do you know that you are doing well after cancer?

Appendix D: Additional Analyses for Paper 1

Sample characteristics and SEM in those diagnosed with breast and colorectal cancer compared to breast and colorectal cancer survivors who completed active treatment.

HINTS Sample 1: Includes respondents diagnosed with breast and/or colorectal cancer. Defines survivors as those diagnosed with cancer.

HINTS Sample 2: Includes respondents diagnosed with breast and/or colorectal cancer who have received and completed treatment for cancer.

Participant Characteristics	HINTS Sample 1 (N = 273)	HINTS Sample 2 (N = 212)
	N (Weighted % ^a)	
Cancer Type		
Breast	200 (70.9)	158 (73.8)
Colorectal	71 (29.1)	54 (26.2)
Time Since Completing Tx		
< 1 year	19 (8.3)	19 (10.0)
1-5 years	57 (19.1)	57 (23.1)
5-10 years	59 (21.7)	59 (26.2)
> 10 years	77 (33.7)	77 (40.7)
Still receiving Treatment	30 (17.3)	-
Missing	31	-
Gender		
Male	32 (15.4)	24 (8.7)
Female	230 (84.6)	184 (91.3)
Missing	9	4
Age Group		
18-49	12 (4.5)	8 (3.1)
50-64	92 (40.9)	70 (37.9)
65-74	77 (25.1)	69 (27.2)
75+	80 (29.4)	60 (31.8)
Missing	10	5
Education		
Less than High School	33 (16.2)	25 (14.8)
High School Graduate	73 (28.1)	57 (27.6)
Some College	74 (27.0)	61 (28.7)
College Graduate or More	84 (28.7)	66 (28.8)
Missing	7	3
Race		
NH White	155 (74.9)	132 (82.1)
NH Black	40 (14.3)	32 (2.8)
Hispanic	24 (6.7)	15 (1.1)
NH Other	15 (4.2)	11 (1.4)
Missing	37	22
Income		
Less than \$20,000	65 (24.0)	54 (25.1)
\$20,000 to < \$35,000	50 (19.6)	37 (17.4)
\$35,000 to < \$50,000	31 (10.2)	24 (8.7)
\$50,000 to < \$75,000	35 (16.9)	28 (19.3)
\$75,000 or More	52 (29.3)	43 (29.5)
Missing	38	26

Participant Characteristics		
	HINTS Sample 1 (N = 273)	HINTS Sample 2 (N = 212)
	N (Weighted % ^a)	
Health Insurance		
Yes	253 (94.6)	199 (95.0)
No	13 (5.4)	10 (5.0)
Missing	5	3

^a Sample and replicate weights were applied to account for the complex survey design and to ensure estimates are representative of the US population. Some values may not equal 100.

Description of HINTS Variables		
	HINTS Sample 1 (N = 273)	HINTS Sample 2 (N = 212)
	Mean (SD) or N (Weighted % ^a)	
Receipt of SCP		
Yes	90 (37.7)	86 (38.1)
No	131 (62.3)	123 (61.9)
Patient-Centered Communication ^b	20.8 (0.3)	20.7 (0.3)
Health Self-Efficacy ^c	3.7 (0.1)	3.7 (0.1)
Aerobic physical activity		
0 min/week	117 (45.1)	84 (39.6)
0-149 min/week	94 (32.1)	76 (32.7)
>150 mins/week	59 (22.8)	51 (27.7)
Fruit/Vegetable Intake		
< 3-5 servings/day	112 (32.5)	84 (33.1)
> 3-5 servings/day	161 (67.5)	128 (66.9)
Tobacco Use		
Never	164 (60.0)	128 (62.0)
Former or Current	104 (40.0)	82 (38.0)
BMI	29.0 (0.7)	28.7 (0.9)
Number of Chronic Conditions	1.6 (0.1)	1.7 (0.1)
Self-reported Physical Health ^c	2.9 (0.1)	3.1 (0.1)

Abbreviations: SD, Standard Deviation

^a Sample and replicate weights were applied to account for the complex survey design and to ensure estimates are representative of the US population.

^b Overall score of the sum of six items on a 4-point likert scale with higher scores indicate higher values on construct (max score 24)

^c 5-point likert scale with higher scores indicating higher values on construct

Standardized Factor Loadings for Latent Structure for Lifestyle Behaviors and Physical Health		
	HINTS Sample 1 (N = 273)	HINTS Sample 2 (N = 212)
Parameters	17	17
Fit Indices		
Chi-Square p-value	0.29	0.23
RMSEA	0.03	.04
CFI	0.98	0.96
WRMR	0.49	0.49
Standardized Item Loadings	<i>b</i> (SE)	
Health Behaviors		
PA	0.98 (0.18)***	0.96 (0.18)***
Smoke	0.19 (0.14)	0.12 (0.16)

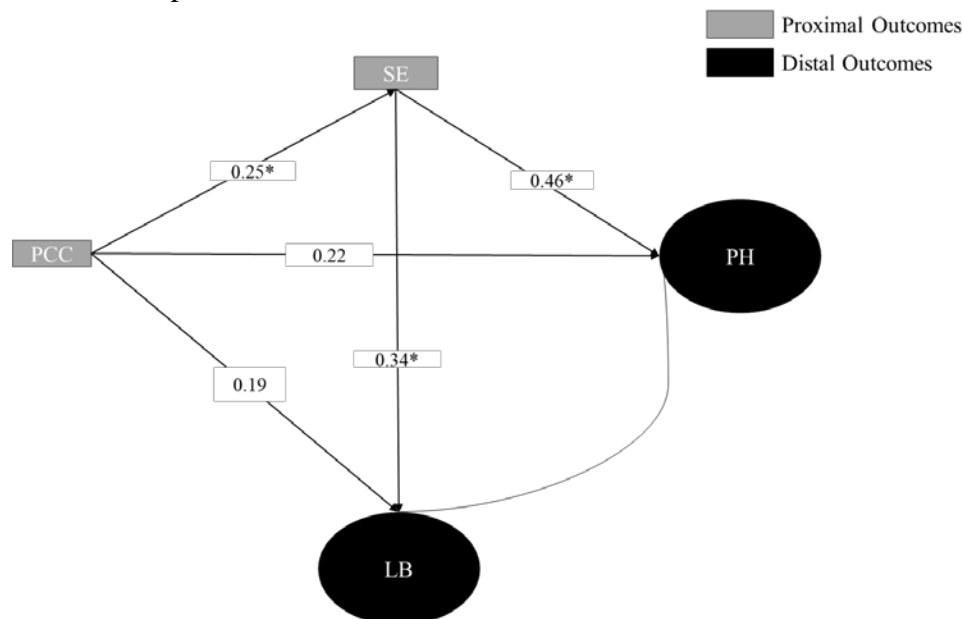
FV	0.41 (0.14)***	0.45 (0.13)***
Physical Health		
Self-reported health	0.55 (0.08)***	0.59 (0.10)***
BMI	-0.53 (0.11)***	-0.47 (0.12)***
# of Chronic Conditions	-0.48 (0.08)***	-0.65 (0.08)***
PH with HB	0.69 (0.14)***	0.63 (0.15)***

* P-value < 0.05

*** p-value < 0.01

Standardized Total, Direct, and Indirect Effects				
	HINTS Sample 1 (N = 273)		HINTS Sample 2 (N = 212)	
	<i>b</i> (SE)	<i>p</i> -value	<i>b</i> (SE)	<i>p</i> -value
Patient-Centered Communication to Physical Health				
Total effect	0.33 (0.12)	0.01	0.34 (0.11)	<0.01
Indirect effect	0.12 (0.05)	0.02	0.11 (0.06)	0.06
Direct effect	0.22 (0.12)	0.08	0.23 (0.12)	0.05
Patient-Centered Communication to Health Behaviors				
Total effect	0.27 (0.12)	0.02	0.27 (0.12)	0.02
Indirect effect	0.09 (0.06)	0.16	0.09 (0.07)	0.21
Direct effect	0.19 (0.11)	0.12	0.18 (0.13)	0.14

HINTS Sample 1 Model



Appendix E: Description of Themes and Domains

Domain	Definition	Supporting Quote
Patient-Provider Communication		
Information Exchange	Description of the information exchange with the provider during the last visit and any communication since the last visit.	<i>I guess just a general little checkup and just letting me know what was coming next as far as just follow up stuff... and it was just you did great, everything turned out- looked like it's working good, your skin looks good um- it was just a real positive appointment, if I'm remembering correctly, and she- just very friendly</i>

		(65 year old, NH white, stage I breast cancer survivor).
Written	Any mention of receiving written information from a healthcare provider and the types of topics covered in the written information.	<p><i>They [oncology providers] provided me with the information. Not just tell me, they also gave me the uh the printout of what I needed to do and how I needed to take care of myself and what to expect (49 year old, NH black, stage III colorectal cancer survivor).</i></p> <p><i>[The papers] you know, stuff like if I have any problems, you know, like stuff like if I'm hurting or sore and stuff like that and it showed me how to take care of the wound that I had on my stomach and stuff like that, and it was just stuff like that, and if I have any problems, you know, I call the nurse if I feel pain and all this stuff- they gave me some pain medicine so I'm good with that (53 year old, NH black, stage II colorectal cancer survivor).</i></p>
Verbal	Any description of what the oncology provider discussed with the patient and the types of topics covered during the discussion.	<p><i>Well, I mean the doctor I have is very matter of fact, you know what I mean? I mean she tells me that it's not completely gone, but that we can- we're just going to have to monitor it and see if it's getting any better, and I mean she's explained to me that nothing is 100% and so therefore as long as we can continue to monitor the cancer that I have and try to prevent it from spreading or getting any bigger that that's pretty much all we can do right now (54 year old, NH white, stage I breast cancer survivor).</i></p> <p><i>They just told me that, you know, like exercise, you know, do the right thing, you know, take care of your body, don't stress out and stuff like that- watch your blood pressure and stuff like that and just take care of yourself. Don't eat the type of food that's going to bring this back (53 year old, NH black, stage II colorectal cancer survivor).</i></p>
Ensuring patient understanding	Description of how the provider makes sure that the patient understands the information received	<i>Well, like I'll talk to the oncologist and then she'll say- [XXX], do you understand?- and I'll be like- Yes. And she'll say- Okay, well explain to me what I told you (54 year old, NH white, stage I breast cancer survivor).</i>
Eliciting questions or concerns	Any mention of the patient asking questions or feeling comfortable asking health related questions	<i>Uh she [provider] actually go over it with me uh and then ask me if I have questions about what she just talked about and if I have a question, I'll ask her (59 year old, NH black, Stage III breast cancer survivor).</i>
Making Decisions	Any mention of how the patient and provider make decisions.	<i>Um, I can't think of any instance where I did not feel that they had given me everything, yeah. I felt- I would say yes they gave me everything I needed (65 year old, NH white, stage I breast cancer survivor).</i>

Responsive/Available	When the patient mentions how the provider makes themselves available to the patient to address their healthcare needs	<i>...she called me back when she did it, and she actually faxed it all for me and called me and let me know that I could come and pick up the original if I needed it. So she's pretty good about following up with anything I need (59 year old, NH black, Stage III breast cancer survivor).</i>
Responding to Patient Needs	Description of how the provider shows interest and sensitivity to patients problem/emotions	<i>I was scared and I told my doctor and they said- We at [hospital], we're always going to take good care of our patients and that's what I like to hear. If a doctor to tell me that, I'm not scared no more (53 year old, NH black, stage II colorectal cancer survivor).</i>
Gaps in Communication	Any mention of what oncologists/nurse/providers could have told the patient following active treatment.	<i>Um, maybe it would be easier for us to take a piece of paper in- like I said, I have a lot of conditions and just to have that listed somewhere on there, because sometimes when I go to the ER, I don't feel like answering a bunch of questions. If they already know, then they can proceed and go ahead... So like even though that way I can tell them what's wrong right that minute and this is all the problems that I have going on because most of the time I end up in ICU anyway (56 year old, NH white, stage II breast cancer survivor).</i>

Oncology Care Teams Responsibilities

Setting up appointments	Any mention of the provider scheduling future follow-up appointments specific to cancer	<i>I mean she's given me all the tools that I need to be able to take care of myself as best I can. I mean like I said, she's got all these appointments scheduled for me, all this lab work scheduled for me ... (54 year old, NH white, stage I breast cancer survivor).</i>
Scheduling labs/radiology	Any mention of the provider scheduling or ordering labs/radiology/or prescribing medication	
Referring patients to other healthcare providers	Any mention of the oncology provider referring patients to other healthcare providers (primary care, specialty, etc.)	<i>He sets up the appointments I ask for and stuff, and he gets to the bottom of the problem. If he can't, he sets you up with somebody else that can. So I talk to him pretty well (56 year old, NH white, stage II breast cancer survivor).</i>
Providing access to outside resources	Any mentions of the oncology provider referring or giving information to patients about support groups and resources outside the healthcare system (exercise classes, nutrition courses, financial assistance, etc.)	<i>They also gave information about exercise programs that are out there uh one at the Baylor Rehab, one at the YMCA's- it was neat to have a group there because one or two people spoke up about other exercise facilities and programs that are available for cancer survivors that [xxx]... (65 year old, NH white, stage I breast cancer survivor).</i>

Adherence Behaviors

		<p><i>Yeah, I had an appointment already set up with another mammo- I can't remember if it's six months or a year, but just to do the breast exam, and if I find something different then let them know and they'll set up an appointment (56 year old, NH white, stage II breast cancer survivor).</i></p>
Cancer Surveillance	Any mention of going to follow up appointments and getting labs/radiology as directed by the oncology care team.	<p><i>Well, I need to continue with all of the followups. I need to have my CT scans done on a regular basis to make sure that none of it has gotten any larger and that it's not in other places, things like that (54 year old, NH white, stage I breast cancer survivor).</i></p> <p><i>I gotta take my pills for five years. Uh-huh, take those pills and I can't run out of them. I always get them, and I take one every- one a day (70 year old, NH black, breast cancer survivor).</i></p>
Engaging in healthy lifestyle behaviors	Any acknowledgement of the need or current engagement in diet, exercise, and smoking cessation.	<p><i>I'm going to listen to them and when they tell me- and like they tell me, Ms. [XXX], you know, they try to help me get off of the cigarettes. I'm going to get off of them cigarettes. They talk to me, you know, and [in case it might] you know you gotta do cause sometimes [it] come back... (70 year old, NH black, breast cancer survivor).</i></p>
Barriers to managing health	Any mention of barriers to getting support or managing health	<p><i>Um, not really uh because I'm not able to afford health insurance so that would be my only thing about me being able to follow up with my health, you know, because of the financial part of it but, you know, I have to worry about that when it happens. (59 year old, NH black, Stage III breast cancer survivor).</i></p> <p><i>I mean they've always told me from the time I had my daughter that I needed to lose weight, and I just never did it so and I mean I've known that I needed to cut down on the sugar and the sweets and the cokes and things like that and there again, I didn't do it. It was my choice not to do it so I can't say that there's any experience that I've had that I wasn't really prepared for (54 year old, NH white, stage I breast cancer survivor).</i></p>
Survivorship Experience		

Physical Health	Any mention of symptoms experiences since completing active treatment.	<p><i>Um, gratefully the fatigue is lessening, and I'm able to get on with doing things that I haven't been able to commit to doing because I didn't know how long I would be fatigued. From the beginning treatment, I can't think of the name of that particular drug in that chemo, a side effect of it has been neuropathy in my fingers and toes. So that's still lingering, but I don't know if I'm just getting used to it or if it's lessening, you know, from time to time I don't even think about it and then like right now it's tingling as I'm- oh, yeah it has that tingling effect in my fingers kind of thing (65 year old, NH white, stage I breast cancer survivor).</i></p> <p><i>Well, I got a lot of other problems other than that so I still stay tired a lot... Yeah from my- and my bones hurt and stuff like that, but it's not from the cancer. It's from everything else that's wrong with me (56 year old, NH white, stage II breast cancer survivor).</i></p>
Mental Health	Any mention of mental health symptoms since completing active treatment.	<p><i>Mentally, uh not very good...Not very good, and I think it's mostly because of not knowing, you know, what the mastectomy would actually look like (59 year old, NH black, Stage III breast cancer survivor).</i></p> <p><i>Well I'm doing well. I never was concerned when I had the cancer. It never did bother me. I never did stress out over it (70 year old, NH black, breast cancer survivor).</i></p>
Pre-Cancer Function	Any mention of being able to do the things they used to be able to do before cancer treatment.	<p><i>So I mean I all in all, I do okay. I'm able to do my own laundry. I can shower myself... Well, I don't have as much pain as I used to have. I'm not quite so tired all the time like I used to be. I definitely have a little bit more energy than I used to have, and the lumps where the masses were have- the swelling in that area I guess is what I'm trying to say, has gone down so like I said, I'm better able to move my arm and my shoulder now than what I used to be able to be (54 year old, NH white, stage I breast cancer survivor).</i></p> <p><i>I can do things that I wasn't able to do after the surgery. Four months after the surgery, I can do it now so I think I'm doing pretty good (59 year old, NH black, Stage III breast cancer survivor).</i></p>
Unexpected Experiences	Anything that the patient did not expect to experience following cancer treatment.	<p><i>Oh I guess I could- there's a lot. I mean, you know, you hear about going through the chemo and all the side effects and I guess I didn't expect it to be as bad as it was with the side effects for the chemo, but I mean I knew about them, I just had never personally experienced them so I wasn't ready for those side effects like the hair loss, the nausea, the vomiting. I wasn't expecting it to be as bad as it actually was (54 year old, NH white, stage I breast cancer survivor).</i></p>

Motivation to stay healthy	Discussion around anything that motivates the respondent to get better after cancer treatment.	<p><i>Well, it's pretty important because I'm trying to stay healthy. I mean I've got a granddaughter that's only nine so yeah it's important to me to stay healthy. I mean she's the only grandchild and her great-grandma [xxx] she's 82. Her great, great aunt she lives with is 74. I mean I gotta stay healthy to be around for her. So I got a motivation. Motivated to stay healthy enough to where I'll be around for a while (56 year old, NH white, stage II breast cancer survivor).</i></p> <p><i>Well, they really motivate me, you know, like I was- you know, I would say to myself I'm a little down and out or something like that. I used to talk to myself, by myself, and say why me and all this stuff. Why do I have to have this, but then when I seen the doctors and stuff, they talk to me about it and I was like- they was telling me don't be scared, don't be nervous and then when they- I just focused on what they was saying to me, and it made me feel better just like telling me that it's going to be okay, you know, we can take it out of you and stuff like that (53 year old, NH black, stage II colorectal cancer survivor).</i></p>
Social Support	Discussion about how family and friends provide support following cancer treatment.	<p><i>Yeah, I can do more stuff and things like that. I mean I try to keep the house around here. They both work, we're roommates so there's- like last night. I couldn't cook. I was nauseous, you know, hey- y'all are going to have to cook. Yeah, so that's just how it works around here when I get sick, I start slowing down, and they're like- I think you need to go get checked out (56 year old, NH white, stage II breast cancer survivor).</i></p> <p><i>My sister-in-law went through this pretty much the same type thing I've gone through a year earlier and so she was able to kinda give me a heads up on some things or if I'd ask her- did you have this or that and she said- oh yeah, that goes away. So it was very helpful. (65 year old, NH white, stage I breast cancer survivor).</i></p>

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